



## PATIENT & CAREGIVER EDUCATION

# Tocilizumab

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

Actemra; Actemra ACTPen; Tofidence; Tyenne

## Brand Names: Canada

Actemra

## Warning

- This drug may raise the chance of infection, including severe infections. Sometimes severe infections have led to death. Most people who had these infections were taking other drugs to lower the immune system like methotrexate or steroid drugs. If you have any infection, are taking antibiotics now or in the recent past, or have had many infections, talk with your doctor.
- TB (tuberculosis) has been seen in patients started on this drug. These patients were exposed to TB in the past, but never got the infection. You may be tested to see if you have been exposed to TB before starting this drug. You will also be watched while you take this drug for signs of TB. Tell your doctor right away if you feel sick or weak, or if you have fever, night sweats, or abnormal weight loss.

## What is this drug used for?

- It is used to treat some types of arthritis.
- It is used to treat a certain artery problem called giant cell arteritis (GCA).
- It is used to treat cytokine release syndrome (CRS).
- It is used to slow the progress of lung disease in some people.
- It is used in certain people to treat COVID-19.
- It may be given to you for other reasons. Talk with the doctor.

## 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 an infection.
- If you have a low white blood cell count or a low platelet count.
- If you have liver disease or raised liver enzymes.
- If you are taking any of these drugs: Abatacept, adalimumab, anakinra, certolizumab, etanercept, golimumab, infliximab, or rituximab.

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?

## All products:

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- You may have more chance of getting an infection. Wash hands often. Stay away from people with infections, colds, or flu.
- If you have high blood sugar (diabetes), talk with your doctor. You may be more likely to get infections.
- If you have had hepatitis B before or carry the virus, talk with your doctor. This drug can cause the virus to become active again.
- Hepatitis B testing needs to be done as you were told by the doctor. Talk with the doctor.
- Drugs that may suppress the immune system like this drug may raise the risk of cancer. If you have questions, talk with the doctor.
- Have your blood work and other lab tests checked as you have been told by your doctor.
- If possible, make sure all vaccines are up to date before treatment with this drug.
- Talk with your doctor before getting any vaccines while taking this drug. Some types of vaccines need to be avoided with this drug.
- You may bleed more easily. Be careful and avoid injury. Use a soft toothbrush and an electric razor.
- Treatment with this drug may lead to higher cholesterol and triglycerides. The effect of these changes on heart health is not known. Talk with the doctor.
- If your weight changes, talk with your doctor. The dose of this drug may need to be changed.
- If you are 65 or older, use this drug with care. You could have more side effects.

- Birth control pills and other hormone-based birth control may not work as well to prevent pregnancy. Use some other kind of birth control also like a condom when taking this drug.
- This drug may cause harm to the unborn baby if you take it while you are pregnant. If you are pregnant or you get pregnant while taking this drug, call your doctor right away.
- If you used this drug when you were pregnant, tell your baby's doctor.
- Tell your doctor if you are breast-feeding. You will need to talk about any risks to your baby.

### **Infusion:**

- Some people have unsafe allergic effects or bad side effects during the infusion or within 24 hours of the infusion. Talk with the 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. Rarely, some allergic reactions have been deadly.
- Signs of infection like fever, chills, very bad sore throat, ear or sinus pain, cough, more sputum or change in color of sputum, pain with passing urine, mouth sores, or wound that will not heal.
- Signs of a urinary tract infection (UTI) like blood in the urine, burning or pain when passing urine, feeling the need to pass urine often or right away, fever, lower stomach pain, or pelvic pain.
- Signs of bleeding like throwing up or coughing up blood; vomit that looks

like coffee grounds; blood in the urine; black, red, or tarry stools; bleeding from the gums; abnormal vaginal bleeding; bruises without a cause or that get bigger; or bleeding you cannot stop.

- Signs of high or low blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- Feeling very tired or weak.
- A fast heartbeat.
- Warm, red, or painful skin or sores on the body.
- A skin lump or growth.
- Change in color or size of a mole.
- Shortness of breath.
- Chest pain or pressure.
- Not able to pass urine or change in how much urine is passed.
- It is not known how this drug may affect some nervous system problems. However, multiple sclerosis (MS) and certain other nerve problems have rarely happened in people taking this drug. Call your doctor right away if you have an abnormal burning, numbness, or tingling feeling; muscle stiffness or weakness; change in bladder or bowel habits; or change in eyesight.
- Tears in the stomach or bowel wall have happened in certain people taking this drug. Call your doctor right away if you have swelling or pain in your stomach that is very bad, gets worse, or does not go away. Call your doctor right away if you throw up blood or have throw up that looks like coffee grounds; upset stomach or throwing up that does not go away; or black, tarry, or bloody stools.
- Liver problems have happened with this drug. Sometimes, these have been severe and have led to a liver transplant or death. Tell your doctor right away if you have any 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.

- Severe skin reactions may happen with this drug. These include Stevens-Johnson syndrome (SJS) and other serious reactions. Sometimes, body organs may also be affected. These reactions can be deadly. Get medical help right away if you have signs like red, swollen, blistered, or peeling skin; red or irritated eyes; sores in your mouth, throat, nose, eyes, genitals, or any areas of skin; fever; chills; body aches; shortness of breath; or swollen glands.

## **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:

- Headache.
- Signs of a common cold.
- Nose or throat irritation.
- Irritation where the shot is given.
- Diarrhea or constipation.
- Anxiety.

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.

## **Prefilled syringes and auto-injectors:**

- It is given as a shot into the fatty part of the skin.
- If you will be giving yourself the shot, your doctor or nurse will teach you how to give the shot.
- Take this drug out of the refrigerator and let it come to room temperature before you use it. Be sure you know how long to leave it at room temperature. Do not heat or microwave.
- 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.
- Move the site where you give the shot with each shot.
- Do not give into a mole, scar, or skin that is irritated, tender, bruised, red, hard, or broken.
- 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.

## **Infusion:**

- It is given as an infusion into a vein over a period of time.

## **What do I do if I miss a dose?**

- Call your doctor to find out what to do.

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

### **Prefilled syringes and auto-injectors:**

- Store in a refrigerator. Do not freeze.
- Store in the outer carton to protect from light.
- Keep dry.
- If needed, you may store at room temperature for up to 14 days. Write

down the date you take this drug out of the refrigerator. If stored at room temperature and not used within 14 days, throw this drug away.

- Protect from heat.

## **Infusion:**

- If you need to store this drug at home, talk with your doctor, nurse, or pharmacist about how to store it.

## **All products:**

- 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.



## **Additional Information**

When used for COVID-19, fact sheets for patients, parents, and caregivers are available to give information to properly inform the adult receiving the drug or, in the case of a minor, the child's parent or legal representative about the risks and benefits of the drug. The provider is required to give a copy of the fact sheet.

<https://www.fda.gov/media/150320/download?attachment>

## **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

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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](http://www.mskcc.org/pe) to search our virtual library.

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