

Ciclosporin

Information for patients



The leaflet contains information about ciclosporin to treat colitis and the common questions patients ask about their medicine.

What is ciclosporin?

Ciclosporin is a drug used to induce remission in acute severe colitis. It is usually started in hospital when patients have not responded to standard treatment for inflammatory bowel disease (IBD), including steroids.

The use of ciclosporin for ulcerative colitis (UC) is **unlicensed**. This means it is being used, as research has shown it to be a useful treatment for this condition. Ciclosporin is an immunosuppressant and is licensed for use in rheumatoid arthritis, psoriasis and organ transplantation.

How does it work?

Ciclosporin works by suppressing (i.e. dampening down) the immune system which is thought to be overactive in UC. When used in a severe flare of colitis, that has not responded to intravenous steroids, ciclosporin has been shown to prevent the need for surgery in the short term in approximately 5 out of 10 patients.

How long does it take to work?

The benefits of ciclosporin can be seen quite quickly, within a few days.

How do I take ciclosporin?

Ciclosporin is often started in hospital and usually initially given to you in a vein, normally in your arm, over 24 hours, for up to 7 days. The dose of ciclosporin is calculated based on your weight.

If you respond to the treatment, this will then be changed to an oral capsule form that is taken twice a day. The oral dose of ciclosporin is calculated based on your weight and will be rounded to the nearest capsule size.

You should always receive the same brand of ciclosporin because the amount of ciclosporin absorbed into the bloodstream may vary between different brands made by different manufacturers. Always check you have been given the same brand of ciclosporin.

You should try to take ciclosporin at the same time every day, with respect to meals, and approximately 12 hours apart. Ciclosporin capsules should be taken with a mouthful of water and swallowed whole. Do **not** take ciclosporin with grapefruit juice as it affects how ciclosporin works.

How long will I be taking ciclosporin for?

Depending on response, it is normally continued for a period of about three months. Do not stop taking the medicine unless your doctor tells you to, however well you feel.

Do I need any special checks when on ciclosporin?

You will be closely monitored when taking ciclosporin and the dose may be adjusted according to clinical response (i.e. your symptoms), ciclosporin blood levels, blood pressure and kidney function. Regular blood tests will be taken to check that there is the correct level of ciclosporin in your blood, and that your kidneys and liver are working properly. You may also be given an antibiotic to take at the same time to decrease your risk of infection. Please let us know if you have any allergies.

When checking the level of ciclosporin in your blood when taking the oral capsules, it is important that you **do not take your dose of ciclosporin on that day until after the blood levels have been taken**.

These blood tests will generally be carried out in the hospital at the phlebotomy clinics. The IBD nurses will contact you if any changes in the dose are needed.

What do I do if I miss a dose of ciclosporin?

If you forget a dose, take it as soon as you remember as long as it is within 6 hours of the scheduled dose. If it is more than 6 hours later than scheduled dose, wait and take the next dose as planned. You should leave 12 hours in-between doses. Do not double up on your next dose, just continue taking the tablets as directed but make a note of it in your diary and remember to tell your doctor on your next visit. If you take too much, then contact your health professional as soon as possible.

What are the possible side effects of ciclosporin?

All medicines have the potential to cause unwanted side effects. Some people taking ciclosporin will experience unwanted side effects initially, however not everyone will get them and as your body adjusts to the medication the side effects may improve over a few weeks. The monitoring of your blood will enable early identification of some adverse effects. Please also refer to the patient information leaflet inside your box of ciclosporin.

Some side effects include, but are not limited to:

- Nausea and tiredness are common
- Increased hair growth
- Enlarged or sore gums which may bleed. If problematic please also arrange to see your dentist, as well as informing the IBD team
- Tremor or shakiness of the hands
- High blood pressure
- Kidney or liver impairment
- High potassium and/or low magnesium
- Increased risk of infections. Please inform a member of your IBD team if you come into contact with chickenpox as you may need preventative treatment
- Headache and abdominal cramps can occur in the early stages
- Hot, burning, numbness in the hands and feet
- Metallic taste in the mouth
- Painful periods or lack of periods.

These will be monitored and generally reversible on reducing dose or stopping.

Does ciclosporin interfere with my other medicines?

Ciclosporin can interact with other medicines including non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or diclofenac or aspirin, St John's Wort and erythromycin. Your IBD team should check your current prescribed medicines for any interactions before you start on ciclosporin.

Always check with your doctor or pharmacist before taking any new medicines whilst on ciclosporin. Please also inform your doctor or pharmacist if you buy any over-the-counter medicines including herbal remedies.

Is ciclosporin safe in pregnancy and breastfeeding?

If you are planning to become pregnant whilst on ciclosporin you should discuss with your doctor and IBD team first. You should not breastfeed if you are taking ciclosporin.

Can I drink alcohol while I am taking ciclosporin at home?

Yes, it is safe to drink alcohol in moderation while you are taking ciclosporin. However, large quantities should be avoided.

Will I need to take any special precautions when taking ciclosporin?

As ciclosporin is an immunosuppressant you are potentially more at risk of infections. Therefore, you should minimise contact with people who have infections, where possible. If you develop a sore throat, an infection or become generally unwell please contact a doctor immediately and **stop your medication**.

Keep all medicines out of the reach of children. Never give any medicine prescribed for you to anyone else. It may harm them even if their symptoms are the same as yours.

Where will I get my supply of ciclosporin?

As it is the hospital initiating treatment with ciclosporin, the supply will generally be issued from the hospital discharge or from the hospital dispensary.

Questions?

If you have any other questions or concerns, you can speak to our IBD nurse helpline. The answer phone number is: **0131 537 1272**

