

What you need to know about ciclosporin in the treatment of inflammatory bowel disease

What is ciclosporin?

Ciclosporin is a powerful immuno-suppressive drug that has been used widely in the field of organ transplantation. Immuno-suppressive drugs work by 'damping down' part of your body's immune system. By damping down your immune response with ciclosporin, we hope to reduce active inflammation in your bowel and reduce the activity and symptoms of your colitis.

How will treatment with ciclosporin help me?

Research suggests ciclosporin has between a 50-80% chance of reducing the symptoms and severity of your colitis. Although ciclosporin may result in the remission of your ulcerative colitis, it does not offer a cure, and does not prevent the colitis relapsing and recurring in the future.

In people with acutely active and severe colitis in hospital (and facing the possibility of surgery), Ciclosporin offers another treatment option (to avoid surgery). However, it is important to note that up to half the people with severe colitis that do not respond to steroid therapy will also fail to respond to ciclosporin. In these cases, the only treatment is to have an emergency colectomy (an operation to remove the inflamed colon), as severe untreated colitis can, in extreme cases, be life-threatening.

When and how will I take the ciclosporin?

Ciclosporin is mainly given on patients that are admitted to hospital with active ulcerative colitis. If your symptoms have not settled despite high dose steroids via a drip straight into a vein (intravenously), the doctor will discuss treatment with you. The exact timing of this would depend on the assessment of the severity of the colitis.

Ciclosporin is given as a tablet. You usually have ciclosporin for about 4-7 days. If in that time your symptoms do not improve, or get worse, then we will discuss surgical options with you. However, if we feel that you have responded well to the ciclosporin, we will continue to monitor your progress with the aim of discharging you home on the ciclosporin.

Eating or drinking grapefruit juice can increase the level of ciclosporin in the blood and increase the risk of side effects so we recommend that you avoid this.

Can I take other medication whilst on ciclosporin?

As ciclosporin is known to interact with some other drugs, it is important that you **do not take any other medications** without first discussing them with the clinical nurse specialist or a doctor. This includes vaccinations and over-the-counter medications.

Is ciclosporin safe?

Ciclosporin has potentially serious (and possibly life-threatening though rare) side effects so we only use it to treat people whose ulcerative colitis is severe and for whom other medical treatments have failed.

Major complications are reported in upto 1 in 5 cases. Side effects include:

- Risk of severe infection
- Flu-like illness, with a sore throat, fever, sweating, headache or shortness of breath
- Rash
- Gout (sudden onset of joint pain and swelling)
- Tremors
- High blood pressure (symptoms may include headaches, red face and disturbed vision).
- Deteriorating kidney function (determined by blood tests at each outpatient visit).
- Severe headaches
- Seizures or fits

It is important that you tell us without delay if you have any of these symptoms

Minor side effects occur in between 3 and 5 out of 10 cases. Less severe side effects may include:

- Gastrointestinal disturbances
- A burning sensation of the hands and feet
- Swollen and bleeding gums
- Fatigue
- Cramps

If you are worried about any of the above, or have any concerns about your colitis and treatment options including ciclosporin contact the clinical nurse specialist, whose number is at the end of this leaflet.

Can anyone be given ciclosporin?

No, some people who suffer, or have suffered from any of the conditions listed below, may not be able to have this treatment. If you do have any of the conditions below you must tell us before you start treatment:

- Cancer
- Infection
- Epilepsy
- Untreated or uncontrolled high blood pressure
- Kidney impairment

You should also tell us if there is a chance of pregnancy so that we can discuss the relative advantages and disadvantages of treatment.

How long will I need to take ciclosporin for?

You will need to take ciclosporin for about 3 months. The dose will be monitored regularly and reduced at intervals by your gastroenterologist.

This drug is used to help you avoid surgery and give enough time for treatment with azathioprine to work.

Shortly after you leave hospital, your gastroenterologist will prescribe you another drug called azathioprine. Azathioprine works in a similar way to ciclosporin but is less potent and due to the lower risk of side effects from it, it may maintain your remission from your colitis better in the long term. However, it can take up to 2 months before the azathioprine starts to work, which is why we don't use it to treat people with severe colitis who need quicker results.

Please let the doctor know if you think you are allergic to any antibiotics.

What monitoring will I need to have whilst taking ciclosporin?

Before you start taking the ciclosporin we will do a number of blood tests to ensure that your kidney, liver and bone marrow are all functioning adequately.

Once you have started the drug you will need blood tests every few days to monitor the levels of ciclosporin being absorbed by your body. You will then need weekly blood tests for the first month, and then monthly tests whilst taking the drug.

On the morning of your blood test you should not take your dose of ciclosporin until after the test.

It is very important that you come to all your out-patient appointments so that we can minimise the risk of your developing any of the side effects related to the treatment.

What if I am planning a family?

We recommend that you put your plans for a family on hold whilst you have this treatment.

Consequently, it is very important that you discuss alternative treatments if you do intend to try for a baby. This applies to both men and women. For more information contact the nurse specialist.

Are there any precautions I should take whilst on ciclosporin?

You should avoid unnecessary contact with anyone that has an infection. This is because ciclosporin is an immuno-suppressive drug and can reduce your ability to fight off infections. If you suspect that you have been in contact with someone with an infectious disease, contact the doctor or nurse specialist immediately for advice.

What if I have any other questions?

If you have any further questions about your treatment please contact the inflammatory bowel disease specialist nurses during office hours:

Sister Kay Greveson & Sister Elaine Cronin k.greveson@nhs.net / elaine.cronin@nhs.net

Tel: 020 7830 2283

If you would like a large print or audio version of this information, please ask a member of staff.