



Inflammatory Bowel Disease (IBD)

Patient information

Ciclosporin

This information leaflet is designed to answer common questions patients ask about their medicine. Further information can be found in the information leaflet supplied by the manufacturer or from your pharmacist or doctor.

Why have I been started on this medicine?

Ciclosporin (cyclosporin, also known as Neoral) is generally reserved for the treatment with severe ulcerative colitis. It is used when patients have not responded to standard treatment for inflammatory bowel disease, including steroids. The use of ciclosporin has been demonstrated to reduce the need for a surgical operation to remove the large bowel (called a colectomy). It is also used in other groups of patients including those with rheumatoid arthritis, psoriasis and with organ transplantation.

How does it work?

Ciclosporin suppresses your body's immune system which led to the inflammation and ulceration of your bowel in the first place.

How long does it take to work?

The benefits of ciclosporin are often seen quite quickly (within days).

What dose do I take?

Some patients in hospital may be started on ciclosporin given intravenously (into a vein) first and then convert to oral medication.

The dose of ciclosporin is initially based on weight (2mg/kg). Once the condition stable this will then be converted into an oral dose given as 2mg/kg twice a day, about 12 hours apart. The dose may be adjusted according to its clinical response, ciclosporin blood levels, blood pressure and kidney function.

How do I take it ?

Neoral (ciclosporin) comes as a gel-filled capsule and is available in four different strengths – 100mg (grey), 50mg (white) 25mg (grey) and 10mg (white). Neoral is also available as a liquid. Neoral is taken twice a day. Ideally the two doses should be taken 12 hours apart at 8.00am and 8.00pm. The times should be fixed as much as possible, to ensure accurate blood levels are obtained, as this will enable appropriate blood levels of [150-250 mcg/L] to be achieved. It is therefore very important that you **don't take your dose of ciclosporin until after blood levels have been taken**. The capsules should be taken with a mouthful of water and swallowed whole. Cyclosporin should be taken on an empty stomach, or at least 1 hour before, or 2 hours after a meal (as food affects its absorption). **Whole grapefruit and grapefruit juice should be avoided** in the hour before you take the capsules as they can increase ciclosporin levels in the blood.

How long will I be taking it?

Patients who respond to ciclosporin usually remain on it for about 3 months. During this period your clinician will start you on alternative therapies to maintain clinical remission, so that the ciclosporin can be weaned off and eventually stopped.

Do not stop taking your medicine unless your doctor tells you to, however well you feel.

What are the common side effects?

Most will not suffer any of these known side effects

- a) Nausea and tiredness are common, but wear off within weeks
- b) Increased hair growth. This can be removed or coloured.
- c) Slightly enlarged or sore gums. If problematic see your dentist.
- d) Tremor or shakiness of the hands.
- e) Headache and abdominal cramps can occur in the early stages.
- f) Hot, burning, numbness in the hands and feet. This normally lessens after a couple of weeks.
- g) Metallic taste in the mouth
- h) Painful periods or lack of periods.
- i) High blood pressure, kidney dysfunction and liver inflammation. All are monitored for as they can be reversed by stopping/reducing dose.
- j) Increased risk of infections. Please alert us if you come into contact with chickenpox, as you may need preventative treatment.

Do I need any special checks while on ciclosporin?

Ciclosporin can raise your blood pressure and affect the kidneys. We recommend that your blood pressure, blood count and kidney function are checked every 2 days for the 1st week, weekly for the next month, every 2 weeks for the 2nd month, then monthly thereafter, as the dose may need adjusting.

What do I do if I experience side effects?

If you feel unwell, develop an infection, sore throat or side effect that you are unsure about contact your doctor, IBD nurse or pharmacist.

What happens if I forget to take a dose?

If you forget to take a dose, take another one as soon as possible, unless it is almost time for your next dose. **Do not double the dose.** If you take too much ciclosporin tell your doctor immediately.

Does ciclosporin interfere with my other medicines?

Ciclosporin can interact with other medicines including non-steroidal anti-inflammatory drugs (e.g. Ibuprofen), St John's Wort and erythromycin. **Always** check with your doctor or pharmacist first. It is safe to drink alcohol in moderation whilst on ciclosporin. Avoid binge drinking as this can seriously affect blood levels of the drug.

Travel Advice

You should avoid having 'live' vaccines such as polio. Most travel vaccines and flu vaccines are, however, acceptable. Discuss with your doctor or pharmacist first.

Is ciclosporin OK in pregnancy and breast feeding?

If you are planning to become pregnant whilst on ciclosporin you should discuss with your doctor first. You should not breast feed if you are taking ciclosporin.

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

For further information you can contact your IBD Nurse Specialist or Gastroenterology specialist.