

Diagnostic and Advisory Service for Neuromyelitis Optica

Patient Information Leaflet

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

CYCLOPHOSPHAMIDE

Why am I being prescribed cyclophosphamide?

Cyclophosphamide is used for several different types of rheumatic disease, including systemic lupus erythematosus (SLE). It is a very powerful drug. One of its actions is to reduce the activity of the immune system (the body's own defence system), and it is only prescribed under very close supervision. Cyclophosphamide is often prescribed along with steroid tablets.

When do I take cyclophosphamide, and what dose will I be prescribed?

There are several different ways in which cyclophosphamide can be prescribed. Your doctor will decide which is best for you and discuss this with you. The dose will depend on your body weight and may change depending on how you respond to the cyclophosphamide. The three main ways are as follows:

- low doses of tablets (usually taken once a day)
- high doses of tablets taken less often (e.g. once every 2 weeks)

Tablets should be taken with or after food (preferably in the morning or early afternoon). They should be taken with plenty of water and swallowed whole (not chewed).

- by injection into a vein (intravenous injection). Your doctor will decide how frequently you should have these injections. The injections need to be given in hospital.

How long will cyclophosphamide take to work?

Cyclophosphamide does not work immediately. It may take 6 weeks or more to produce an effect.

What are the possible risks or side-effects?

A common side-effect is nausea (feeling sick). Your doctor may prescribe medicine to reduce the sickness.

One very important side-effect of cyclophosphamide is inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If this occurs you may notice blood in your urine and you must see your doctor immediately. To reduce the risk of this happening, you should increase the number of non-alcoholic drinks each day to the equivalent of 8–10 glasses of water. Some doctors prescribe a drug called mesna along with cyclophosphamide to try and reduce the risk of cystitis.

Cyclophosphamide can also affect the blood count (one of the effects is that fewer blood cells are made). Taking cyclophosphamide can make you more likely to develop infections. If this happens, or if you have a fever, unexplained bruising or bleeding, you must tell your doctor straight away.

There is a slightly increased risk of certain types of cancer with cyclophosphamide. Discuss this with your doctor.

Other possible side-effects are loss of hair, mouth ulcers, and irregular menstrual periods. If you develop these or any other new symptoms after starting cyclophosphamide, you should tell your doctor or nurse specialist as soon as possible.

If any of these symptoms are severe, you should stop cyclophosphamide and see your doctor immediately.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should stop cyclophosphamide and see your doctor immediately as you may need special treatment. This is because chickenpox and shingles can be severe in people on treatment such as cyclophosphamide which has effects on the immune system. Therefore you may require antiviral treatment.

Do I need any special checks while on cyclophosphamide?

Because cyclophosphamide can affect the blood and the bladder, your doctor will arrange for you to have a blood and urine test before you start treatment and then regular blood and urine checks while on cyclophosphamide. You may be asked to keep a record booklet with your blood and urine test results. Bring this with you when you visit your GP or the hospital. You must not take cyclophosphamide unless you are having regular checks.

May I take other medicines along with cyclophosphamide?

Cyclophosphamide may be prescribed along with other drugs in treating your condition. Some drugs interact with cyclophosphamide, so you should discuss any new medications with your doctor before starting them, and you should always tell any other doctor treating you that you are receiving treatment with cyclophosphamide.

Cyclophosphamide is not a painkiller. If you are already on a non-steroidal anti-inflammatory drug (NSAID) or painkillers you may carry on taking these as well as cyclophosphamide, unless your doctor advises otherwise.

Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

Can I have immunisations while on cyclophosphamide?

It is recommended that you should not be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example rubella immunisation in women of childbearing age), in which case your doctor will discuss the possible risks and benefits of the immunisation with you.

Pneumovax and yearly flu vaccines are safe and recommended.

May I drink alcohol while taking cyclophosphamide?

There is no particular reason for you to avoid alcohol while taking cyclophosphamide.

Does cyclophosphamide affect fertility or pregnancy?

Cyclophosphamide can reduce fertility in both men and women and so, for young patients, it is used only with caution. The effect may be reversible if you stop taking cyclophosphamide.

Cyclophosphamide should not be used by pregnant women. While taking cyclophosphamide, and for at least 3 months after treatment is stopped, both women and men must take contraceptive precautions. If you are planning a family or if you become pregnant while taking cyclophosphamide, you should discuss this with your doctor as soon as possible.

What about breastfeeding?

You should not breastfeed if you are taking cyclophosphamide.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Cyclophosphamide therapy. Make sure you take the monitoring booklet with you to all appointments and pre-assessment clinics. If you do need an operation, in most cases you will be advised to continue taking the Cyclophosphamide.

Where can I obtain further information?

If you would like any further information about cyclophosphamide, or if you have any concerns about your treatment, you should discuss this with your doctor, nurse specialist or pharmacist.

Never give any medications prescribed for you to anyone else