



Cyclophosphamide should effectively treat your condition, and stop it causing damage to your tissues. It has been used for many years and has helped many people. However, as with all drugs some people will have side-effects. This leaflet sets out what you need to know.

### What is cyclophosphamide and how is it used?

In some conditions where the immune system is overactive cyclophosphamide is used to suppress the immune system (by damaging rapidly multiplying cells) to bring the disease process under control.

Cyclophosphamide is used to treat several different types of rheumatic disease, including:

- systemic lupus erythematosus (SLE)
- vasculitis
- myositis
- very occasionally, severe rheumatoid arthritis.

Cyclophosphamide is often prescribed along with steroid tablets or steroid injections.

Cyclophosphamide doesn't work straight away – it may take six weeks or more before you notice an improvement.

You should receive full information about the treatment plan before starting your cyclophosphamide and you may be asked to sign a written consent form.

## When and how do I take cyclophosphamide?

Cyclophosphamide can be taken:

- either through a drip into a vein (intravenous infusion), which will need to be given in hospital
- or as low doses of tablets (usually taken once a day). These should be swallowed whole, not chewed, and should be taken with or after food and with plenty of water.

Your doctor will discuss the options with you. The dose will depend on your body weight and may change depending on how you respond to the drug.

Cyclophosphamide doesn't work immediately – it may be six weeks or more before you feel the benefit. It's important to attend for your planned infusions or take the cyclophosphamide tablets as directed (unless you have severe side-effects):

- even if it doesn't seem to be working at first
- even when your symptoms start to improve (to help keep your condition under control).

#### Possible risks and side-effects

A common side-effect of cyclophosphamide is feeling sick (nausea). Your doctor may prescribe medicine to control this.

Because of its effects on the immune system, cyclophosphamide can make you more likely to pick up infections. It can also make them harder to spot. You should make sure you have repeat blood tests and tell your doctor or rheumatology nurse specialist straight away if you develop any of the following after starting cyclophosphamide:

- a sore throat
- a fever
- any other symptoms of infection
- unexplained bruising or bleeding
- any other new symptoms or anything else that concerns you.

You should stop cyclophosphamide, try to get a prompt blood test and see your doctor immediately if any of the above symptoms are severe. Make sure you attend for regular blood tests while you're on cyclophosphamide.

You should also see your doctor if you get chickenpox or shingles or if you come into contact with someone who has chickenpox or shingles. These can be severe in people who are on cyclophosphamide. You may need antiviral treatment, and your cyclophosphamide may need to be stopped until you're better.

One very important side-effect is inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If this happens you may notice blood in your urine and you must see your doctor immediately. To reduce the risk of this happening, you should drink 8–10 glasses (2–3 litres) of non-alcoholic drinks or water a day. You may be prescribed a drug called mesna to try to reduce the risk of cystitis.

Cyclophosphamide can also affect your blood count, which means your body is making fewer blood cells.

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. You'll then have regular checks while on cyclophosphamide. You may be asked to keep a record of your test results in a booklet, and you should bring this with you when you visit your GP or the hospital.

You must not take cyclophosphamide unless you're having regular checks.

Sometimes cyclophosphamide can cause hair loss, mouth ulcers and irregular menstrual periods.

There's a slightly increased risk of certain types of cancer, particularly bladder cancer, with cyclophosphamide but it will not be recommended for you unless the benefits of treatment are thought to be much greater than the risks. You should discuss this matter with your doctor or nurse specialist.

#### Reducing the risk of infection

- Try to avoid close contact with people who have severe active infections.
- For advice on reducing the risk of infection from food, visit www.nhs.uk/Conditions/Foodpoisoning/Pages/Prevention.aspx

Cyclophosphamide can be given through a drip or as tablets – discuss the options with your doctor.

#### **Taking other medicines**

Cyclophosphamide may be prescribed along with other drugs in treating your condition. However, some drugs can interact with cyclophosphamide, so speak to your doctor before starting any new medications and remember to mention you're on cyclophosphamide if you're treated by anyone other than your usual healthcare team.

- You can carry on taking nonsteroidal anti-inflammatory drugs (NSAIDs) or painkillers if needed, unless your doctor advises otherwise.
- Don't take over-the-counter preparations or herbal remedies without discussing this first with your healthcare team.

#### **Alcohol**

There's no particular reason to avoid alcohol while on cyclophosphamide.

#### **Vaccinations**

It's recommended that people on cyclophosphamide avoid live vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example, rubella vaccination in women of childbearing age).

If you're offered shingles vaccination (Zostavax) it's best if you can have this before starting cyclophosphamide. Shingles vaccination isn't recommended for people already on cyclophosphamide.

Pneumococcal vaccine (which gives protection against the commonest cause of pneumonia) and yearly flu vaccines are safe and recommended.

# Fertility, pregnancy and breastfeeding

Cyclophosphamide can reduce fertility in both men and women, though stopping the drug may reverse this effect. You should discuss this with your doctor, preferably before you start the treatment. There may be options available to help you preserve your fertility if this is important to you, such as sperm storage for men.

Cyclophosphamide shouldn't be used by pregnant women. Men and women taking cyclophosphamide must take contraceptive precautions, and need to continue doing so for at least three months after treatment is stopped. If you're planning a family or if you become pregnant while taking cyclophosphamide, you should discuss this with your doctor as soon as possible.

You shouldn't breastfeed if you're on cyclophosphamide. The drug may pass into the breast milk and could be harmful to your baby.

Try to drink 8–10 glasses of water or non-alcoholic drinks each day to keep your bladder healthy.

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We would like to thank the team of people who contributed to the development of this booklet. It was written by Prof Ariane Herrick and updated by Sue Brown. An **Arthritis**Research UK medical advisor, Dr Steven Young-Min, is responsible for the content overall.

Please note: we have made every effort to ensure that this content is correct at time of publication, but remember that information about drugs may change. This information sheet is for general education only and does not list all the uses and side-effects associated with this drug.



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