Cyclophosphamide is used to treat lupus, vasculitis, myositis, systemic sclerosis, Sjögren’s syndrome and sometimes rheumatoid arthritis.
Introduction
Cyclophosphamide (sy-cloh-fos-fuh-mide) is a drug that can help prevent your condition causing damage to your body. You can discuss the benefits and risks of taking cyclophosphamide with your healthcare professionals before you start treatment, so you’re able to make an informed decision.

What is cyclophosphamide and how is it used?
Cyclophosphamide is type of drug known as a disease-modifying anti-rheumatic drug (DMARD).

It’s used to treat an overactive immune system by targeting cells that cause harm to healthy tissues.

It’s an effective treatment for many people who have developed serious complications as a result of their condition.

It can be prescribed for more severe forms of the following conditions:

- lupus (loo-pus)
- vasculitis (vask-you-lie-tus)
- myositis (my-o-sy-tus)
- systemic sclerosis (sis-tem-ic skle-ro-sis)
- Sjögren’s syndrome (show-grin’s sin-drome)
- very rarely, rheumatoid arthritis (roo-ma-toy-d arth-ri-tus).

Cyclophosphamide is often prescribed alongside steroid tablets or steroid injections.

When and how do I take cyclophosphamide?
Cyclophosphamide can be taken:

- through a drip into a vein. This process is known as an intravenous infusion and is carried out in a hospital or a special clinic.
- as low-dose tablets. These are usually taken once a day. You can take them with or without food, but make sure you swallow them whole with plenty of water.

Your doctor will discuss these options with you.

The dose you’re prescribed will depend on your bodyweight and may change, depending on how you respond to the drug.

Cyclophosphamide doesn’t work straight away. It may take several weeks before you notice an improvement. It’s important to attend your planned infusions or take the cyclophosphamide tablets as directed, even if it doesn’t seem to be working at first.

You should also keep taking it as prescribed when your symptoms improve and you start to feel better, to keep your condition under control.

If you forget to take a dose, contact the healthcare professionals in charge of your care. They can advise on whether you should take the missed dose straight away or just skip it.
Things to know before taking cyclophosphamide

Cyclophosphamide is a very effective drug for many patients. But not everyone will be able to take it.

Whether you can be prescribed cyclophosphamide will depend on what treatments you’ve tried before and the severity of your condition.

Before starting cyclophosphamide, your doctor will need to check if you’ve ever been exposed to tuberculosis (TB), as well as hepatitis B and C. This is because cyclophosphamide can increase the risk of these conditions starting up again. If the tests are positive, you may need a course of treatment to tackle these first.

Your doctor will also arrange a series of urine and blood tests before and during treatment to assess whether this drug is right for you. 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.

What are the possible risks and side effects?

As with all drugs, cyclophosphamide has potential side effects. If you have severe side effects or are concerned about any of your symptoms, contact one of the healthcare professionals in charge of your care.

A common side effect of cyclophosphamide is feeling or being sick. Your doctor may prescribe medication to control this.

Because of its effects on the immune system, cyclophosphamide can make you more likely to develop symptoms of a cold or to pick up infections. You should tell your doctor or rheumatology nurse straight away if you develop any of the following symptoms after starting cyclophosphamide:

- a sore throat or a cough
- a high temperature or a fever
- a rash.

Contact your rheumatology team if you get chickenpox or shingles, or if you come into contact with someone who has them and you have never had chickenpox before. These illnesses can be worse than usual if you’re taking cyclophosphamide. You may need treatment for them and your cyclophosphamide may need to be stopped until you’re better.

If you notice blood in your urine, see your doctor as soon as possible. This could be a sign of cystitis (sis-tye-tis), a condition caused by inflammation of the bladder walls.

To reduce the risk of this happening, you may be asked to drink 8–10 glasses (2–3 litres) of fluids a day during your treatment. You may be prescribed a drug called mesna to try to reduce the risk of cystitis.

Cyclophosphamide can sometimes cause a decrease in your blood count, liver problems, hair loss and mouth ulcers.

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

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry around a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you’re a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

Taking other medicines

Cyclophosphamide may be prescribed alongside other drugs to treat your condition. However, some drugs can interact with cyclophosphamide, so speak to your doctor before starting any new medications.

Remember to mention you’re on cyclophosphamide if you’re treated by anyone other than your usual rheumatology team, as it won’t appear on your repeat prescription list from your GP.

You can carry on taking non-steroidal anti-inflammatory drugs (NSAIDs) or painkillers if needed, unless your doctor advises otherwise.

Don’t take over-the-counter preparations or herbal remedies without talking to your healthcare team or pharmacist first, as some of them may react badly with cyclophosphamide.

Vaccinations

The pneumonia (nyoo-moh-nee-uh) vaccine and yearly flu vaccines are safe and recommended when taking cyclophosphamide. It’s very important to have these to reduce your risk of infection. Try to have these vaccines before starting cyclophosphamide to give the vaccines plenty of time to work.

Avoid having live vaccines such as MMR (Measles Mumps and Rubella) or yellow fever. Vaccines for chickenpox and shingles are also live and should be avoided.

However, if you’ve never had chickenpox, it can be good to be vaccinated against it before starting cyclophosphamide. But discuss this with your rheumatology team first.

It’s also a good idea to get any family or household members vaccinated against chickenpox before you start taking cyclophosphamide.

If you’re unsure about whether you should be having a vaccine, make sure to have a chat with your rheumatology team.

Alcohol

Drinking alcohol doesn’t cause any problems for the majority of people who take cyclophosphamide. However, some people find that the combination of alcohol and cyclophosphamide can cause them to feel or be sick.

Try to stick within the government guidelines, which say that men and women should have no more than 14 units of alcohol a week. This is equivalent to about six glasses of wine or six pints of beer.

You can find out more about units of alcohol at www.drinkaware.co.uk
Fertility, pregnancy and breastfeeding

Cyclophosphamide can affect your fertility. This is your ability to become pregnant or father a child. If this is an issue for you, speak to your doctor before you start treatment.

Cyclophosphamide shouldn’t be used by pregnant women or women planning pregnancy in the immediate future. Men and women taking cyclophosphamide should use contraception. It’s advised that women should continue using contraceptives for a year after treatment ends, and that men should do so for six months.

If you’re planning a family or you become pregnant while taking cyclophosphamide, talk to your doctor as soon as possible.

You shouldn’t breastfeed if you’re on cyclophosphamide as it could pass into your breast milk.

Thank you!

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This leaflet is a guide to cyclophosphamide, its benefits and potential side effects. If there’s anything else you’d like to know about this drug, just ask the healthcare professionals in charge of your care.

You can also call our free helpline on 0800 5200 520, where our trained advisors can offer information, support and advice on your type of arthritis.

Visit our website www.versusarthritis.org to find out more.