

Cyclophosphamide Intravenous Chemotherapy (IV chemo)

The Covid pandemic has had a significant impact on the NHS ability to provide routine elective services. We recognise that patients are waiting longer than we would all like and it is not always possible to identify when treatment will take place. This document provides you with information on how you are able to support yourself while waiting to attend the hospital. The guidance has been written by clinicians who are responsible for your care.

Please read the following information in conjunction with the staying healthy guidance and also the clinical guidelines for your specific procedure/condition.

Introduction

Cyclophosphamide is type of drug known as a [disease-modifying anti-rheumatic drug \(DMARD\)](#).

When people have an autoimmune condition, the body's immune system can mistakenly cause harm to healthy tissues. Cyclophosphamide can stop this happening by reducing the effects of the overactive immune system.

It can be prescribed for more serious 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).

Who can take cyclophosphamide?

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

You will need to have tried other drugs to treat your condition before you can be prescribed cyclophosphamide.

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 check 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.

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How is it take?

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.

Side effects and risks

As with all drugs, cyclophosphamide can sometimes cause 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 anti-sickness 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 skin 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.

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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.

Effects on other treatments

Cyclophosphamide may be prescribed alongside other drugs to treat your condition, or example [steroid tablets](#) or [steroid injections](#).

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

It's usually recommended that people on cyclophosphamide avoid live vaccines such as measles, mumps and rubella (MMR), chickenpox and yellow fever. But sometimes a live vaccine may be necessary, so you should discuss this with your rheumatology team.

If you've never had chickenpox, it's good to get a vaccination 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.

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The Zostavax shingles vaccine is a live vaccine and isn't recommended for people who are on cyclophosphamide. However, a non-live shingles vaccine (Shingrix) is available so you may be able to have this instead.

It's recommended that you have the vaccination against COVID-19. It's recommended that you have the pneumonia vaccine and yearly flu vaccine injection while taking cyclophosphamide. These vaccines are not live, so it's safe for you to have them.

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

Having an operation

If you are due to have surgery talk this over with your specialists. You may be advised to stop cyclophosphamide for a few weeks before and after your surgery.

Alcohol

Drinking alcohol doesn't cause any problems for most people who take cyclophosphamide. Some people find 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. It's best not to save your 14 units up and have them all at once, and try to have at least two alcohol free days a week.

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.

You shouldn't take cyclophosphamide if you're pregnant or trying to get pregnant. 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.

What should I do if my health is deteriorating?

If your health is deteriorating, you need to be seen by your GP for review and further assessment and management. If it needs urgent attention please contact NHS 111.

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Contact Us

UHCW NHS Trust Rheumatology Day Unit

Telephone: 024 7696 6031 (Day Unit)

Rheumatology Helpline: 024 7696 5723

Rheumatology secretaries: 024 7696 6707 and 0247696 6705

For the Rheumatology helpline it is an answerphone service for patients under the care of the Rheumatology Department at University Hospital Coventry (UH) and Rugby St Cross Hospital (RStX). Calls are listened to by the nurse Monday-Friday (except bank holidays) between 8am – 3pm. We will respond to your email within 48hrs. To leave a message please include:

- Full Name
- Your hospital number (this starts with a letter of the alphabet) or your 10 digit NHS number or Date of Birth
- Contact telephone number
- Reason for your call

For more support and information please visit:

Versus Arthritis: www.versusarthritis.org

National Rheumatoid Arthritis Society (NRAS): www.nras.org

National Ankylosing Spondylitis Society (NASSS): www.Nass.co.uk

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