

# Cyclophosphamide in Acquired Haemophilia A

**This leaflet aims to answer your questions about taking cyclophosphamide to treat your acquired haemophilia A. If you have any questions or concerns, please speak to a doctor or nurse caring for you.**

## What is cyclophosphamide?

Cyclophosphamide is a medicine that can be used to suppress your immune system. It also interferes with how your body produces new cells and therefore it is classed as chemotherapy. It is an effective treatment for acquired haemophilia A and other autoimmune conditions. In acquired haemophilia A your immune system has been triggered to neutralise the factor VIII (eight) that your body makes naturally. This causes you to have bruising and other bleeding symptoms as your body is no longer able to stop bleeding as it normally would. Cyclophosphamide works by depleting the cells in your body that are neutralising your clotting factors so your factor VIII can work as it should.

## How do I take the medicine?

Swallow the tablets whole, with a full glass of water. They should not be chewed or crushed. Take them early in the day. Take them at the same time every day. Please stop taking the tablets on the exact date you are advised to and return any unused tablets to the hospital so that we may dispose of them safely. It is important that you wash your hands thoroughly with soap and hot water after handling cyclophosphamide tablets. If a carer is dispensing the tablets for you, they must wear disposable gloves (these can be supplied from the hospital) and wash their hands afterwards.

## What should I do if I forget to take the medicine?

If you forget to take the capsules or tablets, you should take the missed dose as soon as possible, within the same day. If a full day has gone by, let your doctor or nurse know. Do not take a double dose. If you are sick after taking your cyclophosphamide tablets, please contact a doctor or nurse. Do not take another dose.

## Are there any side effects?

You will be taking cyclophosphamide at a low dose for a short amount of time, usually thirty days. The most common side-effects experienced by people with acquired haemophilia taking cyclophosphamide are thinning hair, fatigue and

nausea. Be sure to rest as much as you need to and if you are experiencing nausea please mention it to your doctor or nurse as there are medicines we can give you to help with this symptom.

Taking cyclophosphamide can make you more susceptible to infection and you may get more unwell than the average person. Contact the hospital immediately if you have a temperature above 37.5 or below 36.0 degrees Celsius, any other signs of an infection or if you feel generally unwell. Avoid people who are unwell and follow NHS guidelines on avoiding food poisoning. Please also inform us if you are exposed to anyone with chicken pox or shingles as we may need to give you extra treatment to protect you.

**The following side-effects are normally experienced by patients taking cyclophosphamide at a much higher dose for a longer time, but it is important for you to be aware of them in the event you experience any of these symptoms.**

- Cyclophosphamide can cause inflammation in your bladder that can result in bleeding. This is known as haemorrhagic cystitis. Please contact the hospital immediately if you have any burning, stinging or pain when you pass urine, or if you notice any blood in your urine – the colour can often turn red or rose. To help avoid this, please ensure you are staying well-hydrated throughout the day.
- Cyclophosphamide can affect your body's ability to make blood cells. We will be checking your blood count regularly to monitor this while you are on this medicine.
- Sometimes people taking cyclophosphamide may experience mouth ulcers, irregular menstrual bleeding or hair loss. We would not expect this to happen at the dose you will be given.
- There's a slight increased risk that people who have been treated with cyclophosphamide will go on to develop cancer, particularly bladder cancer. Again, this information was gathered on patients taking cyclophosphamide at much higher doses for a longer time.

You would not be offered cyclophosphamide if we did not believe the benefits of this treatment outweigh the potential risks.

## Is there anything else I need to know?

### **Storage:**

Please store your cyclophosphamide securely and out of reach of children.

### **Fertility:**

Cyclophosphamide can reduce fertility in both men and women, though stopping the drug may reverse this effect.

Men and women taking cyclophosphamide should take contraceptive precautions for at least three months after finishing treatment.

If you have sex whilst taking cyclophosphamide tablets, you need to use a condom. This is to protect your partner in case there is any chemotherapy in your semen or vaginal fluids.

### **Pregnancy/breastfeeding:**

Cyclophosphamide is not safe to take during pregnancy.

Cyclophosphamide can be passed on in breast milk. Therefore do not breastfeed whilst you are receiving this medication as it may be harmful to your baby.

### **Vaccinations:**

Please discuss any vaccinations with the haemophilia team prior to receiving them.

It is generally recommended that people receiving cyclophosphamide avoid live vaccines such as yellow fever.

### **Herbal Remedies and over the counter medication:**

Please do not take herbal remedies or new medication without first discussing it with the haemophilia service.

**During treatment with cyclophosphamide you should avoid grapefruit and grapefruit juice. You should also avoid the herbal remedy St John's Wort. This is because they can make cyclophosphamide less effective and may increase side effects.**

## Useful sources of information

<https://rarediseases.org/rare-diseases/acquired-hemophilia/>

<https://www.nhs.uk/live-well/eat-well/10-ways-to-prevent-food-poisoning/>

This leaflet was produced based on information obtained from Macmillan and Arthritis Research UK.

## Contact us

If you have any questions or concerns about cyclophosphamide, please contact the haemophilia office on 020 8725 0763 (Monday to Friday, 8am to 5pm). Out of hours, please contact the haematology registrar via the hospital switchboard.

If your query is in regards to your appointment for your blood test please call the Haematology Day Unit on 020 8725 1680.

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

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## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111

### AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website ([www.accessable.co.uk](http://www.accessable.co.uk)). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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