

Cyclophosphamide treatment in autoimmune blistering disease

This leaflet explains more about having treatment with the medicine cyclophosphamide for an autoimmune blistering disease. It includes information about the benefits, risks and alternatives and what you can expect when you come to hospital for the treatment.

If you have any further questions, please speak to a doctor or nurse caring for you.

Along with this leaflet it is important that you read the following leaflet:

- Our leaflet, **Unlicensed medicines – a guide for patients** – if you do not have a copy, please ask your nurse for one.

What is cyclophosphamide?

Cyclophosphamide is a type of medicines called an immunosuppressant. This means that it reduces the activity of the immune system (the body's own defence system). It is often prescribed alongside corticosteroids so that you need lower doses of corticosteroids each day. It can be given orally (by mouth) or as an infusion through a vein (intravenous infusion).

At higher doses, it is used to treat some kinds of cancer.

What are the benefits - why should I have cyclophosphamide?

The aim of the treatment is to reduce the symptoms of your condition and it is also used to lower your dose of corticosteroid, which will help to lower the risk of side effects associated with corticosteroid treatment.

What are the possible side effects?

Cyclophosphamide can lead to infertility in both men and women, which in some cases may be irreversible. If you are planning a family or your family is not yet complete, please discuss this with your doctor before starting the treatment.

The following are some of the more common side effects associated with cyclophosphamide treatment, which you may or may not experience. As the dose of cyclophosphamide used in the treatment of autoimmune blistering diseases is lower than that used for other conditions, some of these may be less likely to occur.

We will talk to you about how to deal with these side effects if you experience them. Please call us if you have any concerns – our contact details are listed at the end of this leaflet.

- Nausea and vomiting – doctors can prescribe anti-sickness medicines to help relieve these symptoms.
- Headaches.
- Mouth ulcers.
- Hair loss – in most cases this is reversible.
- Irregular menstrual periods.
- Shortness of breath due to scarring (fibrosis) of the lungs (with prolonged use).
- Inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If you are having intravenous treatment, you will be given another medicine (mesna) to help protect the lining of the bladder and reduce the risk of developing this side effect. If you are having oral treatment, you are advised to drink plenty of water throughout the day to reduce the risk of this side effect occurring. If you experience a burning sensation while urinating or notice blood in your urine, please contact your doctor straight away so that they are aware.
- Reduced level of white blood cells making you more susceptible to infection. If you develop a fever, sore throat or other symptoms of infection or get any unexplained bleeding or bruising you should tell your doctor straight away.
- A corticosteroid infusion may be administered with intravenous cyclophosphamide which may cause alertness in the day and difficulty in sleeping in the night after treatment.
- There is slightly increased risk of certain types of cancer with cyclophosphamide – you should discuss this with your doctor.

For a complete list of the known side effects please refer to the manufacturer's information leaflet supplied with this medicine.

Pregnancy and breastfeeding/fathering children advice

Cyclophosphamide may cause birth defects when taken during pregnancy. If you are sexually active and able to have children it is essential that you use a reliable form of contraception while taking cyclophosphamide. Please ask your doctor or nurse if you would like further information. You should discuss with your consultant before trying to have a baby so that a careful plan can be made to alter your treatment.

Women – do not take cyclophosphamide if you are pregnant or breastfeeding. It is recommended that you wait a minimum of six months after finishing your treatment before trying to become pregnant. Should you become pregnant while on treatment, stop taking your cyclophosphamide immediately and arrange an appointment with your GP as soon as possible. Before each treatment you may be asked to take a pregnancy test.

Men – it is recommended you wait a minimum of six months after finishing treatment before trying to father a child as your sperm can be affected. You should use effective contraception. Talk to your doctor or nurse if you need advice.

Taking an unlicensed medicine

There are times when doctors advise patients to use a medicine in a way not specified by the manufacturer of the medicine because they think it may work well to treat a particular condition. Cyclophosphamide is not licensed for the treatment of autoimmune blistering diseases (such as pemphigus vulgaris) in the UK. If you would like more information about unlicensed medicines please ask for a copy of our leaflet, **Unlicensed medicines – a guide for patients**. Alternatively, you can call the Pharmacy Medicines Helpline (contact details are at the end of this leaflet).

If the tablets are prescribed for you, please do not share them with others, even if their symptoms are the same as yours because the tablets may harm them. Please store the tablets in an area that is not accessible to others living with you to avoid them being mistaken for other tablets.

Are there any alternatives?

There are many different treatments for autoimmune blistering disease including steroids and other immunosuppressants, such as azathioprine and mycophenolate mofetil. Some patients are also treated with an intravenous infusion of immunoglobulin. Your doctor may have discussed or tried these alternatives before referring you for treatment with cyclophosphamide.

How can I prepare for cyclophosphamide?

You will have a blood test shortly before treatment (within two days) to make sure that you are fit to have cyclophosphamide. This will check your blood count and kidney function. These will also be monitored regularly while you are having the treatment.

Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

How will cyclophosphamide be given?

Cyclophosphamide can be given in one of two ways:

1. In tablet form on a continuous basis (this is a maintenance therapy that you may or may not require). 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).
2. In hospital as an intravenous infusion into a vein in your arm through a thin plastic tube called a cannula. The infusion usually takes about 30 minutes.

Cyclophosphamide is often used in a 'pulsing' regime, where the drug is given intravenously once a month. This is often combined with three daily steroid injections and daily low dose cyclophosphamide tablet treatment to be taken on the days between the monthly infusions. If you are on the pulsing regime, oral cyclophosphamide should be taken every day except the day of the intravenous cyclophosphamide.

Because the intravenous treatment occurs in hospital over three consecutive days each month, you will need to consider arrangements for work commitments and dependents, as you are likely to need to take a whole day off work for each treatment session.

The length of time you will need to take cyclophosphamide for will depend on your individual circumstances – we will talk to you about how long you will need the treatment for.

Will I feel any pain?

You may feel some discomfort when the cannula is placed in a vein in your arm. This should only last for a few seconds and then wear off. If you continue to feel discomfort or notice swelling around the cannula please tell your nurse

Can I take other medicines alongside cyclophosphamide?

Please let us know about any medicines you currently take, including those prescribed for you and any you buy over the counter, including vitamins, supplements and herbal/alternative medicines. We will check through them to make sure that they are suitable to be taken with cyclophosphamide and any other medicines that you will be given during your course of treatment.

You should discuss any new medicines with your doctor before starting them and you should always tell any other doctor treating you that you are on cyclophosphamide. Do not take over-the-counter preparations or herbal medicines without discussing this first with your doctor, specialist nurse or pharmacist.

If you take certain medicines for diabetes (for example gliclazide, glipizide or glibenclamide) you may need to monitor your blood sugar levels more closely. This is because cyclophosphamide can cause these medicines to have an increased effect on lowering blood sugars.

Can I have vaccinations?

If you are on cyclophosphamide you must avoid live vaccines such as yellow fever, varicella, zoster and MMR. If you require live vaccinations, you should discuss this with your doctor or specialist nurse first to ensure that they are safe to have while you are on this treatment. The annual flu vaccine does not interact with cyclophosphamide and is recommended.

What happens after the treatment?

You will be monitored by the nurses in the outpatient infusion suite at Guy's Hospital for at least two hours after the treatment. The treatment can last for three consecutive days – you can go home after treatment each day. However, if you have a long way to travel, we may be able to provide hospital accommodation for the three days you are being treated. Please speak to your doctor or nurse in clinic about this.

What do I need to do after I go home?

The infusions may make you feel tired so please rest that evening and take it easy for a few days afterwards. If the steroid medicine has made you feel alert you should still try to take it easy. To reduce the risk of cystitis, we recommend that you drink at least three litres (six pints) of fluid on the day of the treatment and for three days afterwards.

Because of its effect on the immune system, cyclophosphamide may make you more likely to pick up infections. You should therefore avoid close contact with anyone who has a severe active infection, for example pneumonia, influenza, and kidney infections.

Will I have a follow-up appointment?

You will have a follow-up appointment in the immunobullous clinic every three months – this may be more frequent at the start. You will be reviewed by one of the doctors in the outpatient infusion suite at Guy's Hospital each time you come in for an infusion.

Contact us

If you have any questions or concerns about cyclophosphamide, please contact Dr Grove's team on **020 7188 6279 / 7847** (Monday to Friday, 9am to 5pm).

Out of working hours, the dermatology on-call team can be contacted through the hospital switchboard by calling **020 7188 7188** – state 'bleep desk' and then ask for bleep **2010**

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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