NHS
Lancashire Teaching Hospitals
NHS Foundation Trust

Information for patients and carers

Cyclophosphamide

What is Cyclophosphamide?

The immune system is the body’s defense mechanism against infection. In certain illnesses this mechanism becomes inappropriately activated to target parts of the body. This type of illness is called an auto-immune disease. Cyclophosphamide is a medication that will lower the activity of the immune system to help treat disease. You may have heard of cyclophosphamide before in the context of treating cancers.

Prior to treatment with cyclophosphamide, you will have blood tests to check for evidence of viral infections, including hepatitis and HIV as part of a routine screen. In the event of a positive result your treatment plan will be reviewed and may need to be changed. Cyclophosphamide can be given as daily tablets or by a series of infusions into a vein and begins to work within ten days. It has a very long track record as a highly effective treatment for different autoimmune conditions, including vasculitis, lupus and nephrotic syndrome. In conditions such as vasculitis, it is preferable to give cyclophosphamide as an infusion every two to three weeks as the overall dose and therefore potential side effects will be less compared to tablets, but control of disease is just as good. You may need up to ten infusions over a three-to-six-month treatment period. The dose of cyclophosphamide is calculated according to your age, weight and kidney function. Infusions are given as a day case over 1-2 hours.

How will treatment be monitored?

If given intravenously, you will need blood tests 1-2 days before a planned dose and repeat bloods tests 7-10 days after a dose is given. If given as a tablet you will need blood tests every 1-2 weeks. If the level of any of your blood cells is low, your next treatment may be delayed, and the dose may need to be reduced.

What are the possible side effects of cyclophosphamide?

As with all medications, side effects are possible but will not affect everyone. Some people have very few side effects while others may experience more, but the benefits of treatment usually far outweigh the risks. The following are some of the potential side effects that can occur:

Feeling sick & vomiting: Feeling sick and sometimes being sick is the most common side effect. If it does happen it may begin a couple of hours after the treatment is given and last for up to 24 hours. To try and reduce the possibility of this, you will be given an anti-sickness injection before each cyclophosphamide infusion. If the sickness continues, anti-sickness tablets can be prescribed to take home with you.

Bladder irritation: One of the by-products of cyclophosphamide appears in the urine, which can cause irritation to the bladder wall and bleeding. To protect your bladder, you will be given a medication called mesna as an infusion and tablets. Drinking plenty of fluids and frequent urination will also help prevent any irritation. If you are on a fluid restriction diet because of kidney failure, check with your doctor before increasing your fluid intake.

Infection: Cyclophosphamide works by reducing the activity of your bone marrow. This is the part of the body that produces the cells of your immune system which fight infection (white blood cells), as well as cells that carry oxygen around the body (red blood cells) and cells that help stop bleeding (platelets). As a result, cyclophosphamide will place you at increased risk of infection. You will have regular blood tests to check your blood count. If the level of any of your blood cells is too low, your next treatment may be delayed, and the dose may need to be reduced. To try and minimise the risk of infection, you will also be started on two preventative antibiotics – fluconazole and co-trimoxazole.

Hair loss: Some hair loss or thinning can occur during treatment. It is more likely at higher doses of cyclophosphamide used to treat other conditions and less likely with the lower doses used to treat vasculitis.

Mouth ulcers & sores: This is not common at the doses used to treat vasculitis. If your mouth becomes sore or you notice small ulcers, tell your doctor who can prescribe specific mouth washes for you. We also advise check-ups with your dentist.

Liver function: Cyclophosphamide can affect your liver function; however this is not common at the doses used to treat vasculitis. If this does occur, any changes are usually temporary and go back to normal when treatment is finished. Your liver function will be monitored as part of your routine blood tests.

Cancer: As well as fighting infection, another job of the immune system is to detect and get rid of any potential cancerous cells in the body. The potential risk of cancer in the future goes up with any treatment that lowers the activity of the immune system. With long-term use of cyclophosphamide there is a very small risk of developing cancer in the future. Giving cyclophosphamide as an infusion means that the overall dose that is generally used to treat vasculitis is lower, which will help reduce the cancer risk. To help reduce this risk further we strongly advise you to participate in any national screening programmes offered to you for breast, cervical, prostate and bowel cancer. We also recommend avoiding sunbathing. When you do go out in the sun, to reduce the likelihood of skin cancer we recommend using high factor sunblock.

Fertility: Cyclophosphamide may reduce fertility and the ability to have a child in people of any gender. In women, it can cause irregular menstrual periods or bring forward the menopause. Please discuss options to try and help preserve your fertility if this is a concern.

Other guidance

Pregnancy & breast feeding: Cyclophosphamide should not be given during pregnancy or if you are breast feeding. Pregnancy is not recommended during treatment and during the 6 months after finishing treatment. We also recommend the use of contraception while on treatment and for at least 6 months after treatment has stopped.

Can I take other medications while on cyclophosphamide? Before starting a new medication, you should always tell the prescribing doctor that you are taking Cyclophosphamide. Please check with your doctor or pharmacist before taking any ‘over the counter’, herbal or complementary medicines.

Can I have vaccinations while on cyclophosphamide? As Cyclophosphamide lowers your immune system and ability to fight infection, it will also reduce the effectiveness of any administered vaccine. Live vaccines should be avoided while you are on treatment. Talk to your doctor before having any vaccinations while you are receiving treatment with cyclophosphamide.

Can I drink alcohol while taking Cyclophosphamide? Yes, in moderation and within current recommended safe limits, although alcohol can increase the risk of feeling sick.

What are the alternatives?

Based on your individual needs and understanding of the disease, your team have recommended treatment with cyclophosphamide. Other medications may be considered depending on the disease being treated. There is also the option not to undertake any treatment. The lack of any treatment would carry a significant risk of uncontrolled disease, organ damage and death.

Contact details

Should you require further advice or information please contact the Renal Department on telephone: **01772 522739.**

Sources of further information

www.lancsteachinghospitals.nhs.uk
www.nhs.uk
www.accessable.co.uk
www.patient.co.uk
www.lancsteachinghospitals.nhs.uk/veteran-aware
https://bepartofresearch.nihr.ac.uk/

Lancashire Teaching Hospitals NHS Foundation Trust is not responsible for the content of external internet sites.

If you would like any further information or have any questions about your planned treatment, please speak with your consultant and treating team. More information about vasculitis can be found on the Vasculitis UK and Versus Arthritis websites which are listed below.

The Northwest Vasculitis Support Group is made up of patients in the Lancashire region. They are a great source of patient support, also welcome family, friends and carers.

Vasculitis UK - www.vasculitis.org.uk

Versus Arthritis - www.versusarthritis.org

Northwest Vasculitis Support Group - nwvasculitis@outlook.com

All our patient information leaflets are available on our website for patients to access and download:

www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

Lancashire Teaching Hospitals is a smoke-free site. Smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking this will include Nicotine Replacement Therapy to help manage your symptoms of withdrawal and the opportunity to speak to a nurse or advisor from the specialist Tobacco and Alcohol Care Team.

If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638.**

Please ask a member of staff if you would like help in understanding this information.
This information can be made available in large print, audio, Braille and in other languages.

Our patient information group review our leaflets regularly, if you feel you would like to feedback on this information or join our reading group please contact on email address:
patientexperienceandinvolvem@LTHTR.nhs.uk

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