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# Patient Information

# Intravenous Cyclophosphamide

Renal Department

# Intravenous Cyclophosphamide

This patient information leaflet is for patients who have been prescribed intravenous (IV) cyclophosphamide by the renal team. The leaflet is not meant to replace talking to your doctor about your condition or treatment. Please speak to your doctor if you have any questions about your treatment with intravenous cyclophosphamide.

## The immune system

The immune system makes antibodies and immune cells, which are in the blood to help your body to fight infections, such as those caused by bacteria and viruses. In certain illnesses the immune system becomes too active and fights the person's own body instead of helping to protect it. These kinds of diseases are called auto-immune diseases. Two examples of an auto-immune disease are Systemic Lupus Erythematosus (SLE) and Vasculitis.

## How does intravenous cyclophosphamide work?

Intravenous cyclophosphamide works by "damping down" the over active immune system.

## Why am I being prescribed intravenous cyclophosphamide?

Cyclophosphamide is licensed to treat a wide range of cancers, and other diseases, such as SLE and vasculitis.

Cyclophosphamide can be given as a daily tablet or intravenously (into a vein), called a **bolus injection** every few weeks. Bolus intravenous cyclophosphamide is recommended where disease is severe or tablets have not worked. Also, the total dose given with a course of intravenous treatment is about half that of a course of oral treatment.

This is useful if there are worries about the effect of cyclophosphamide on fertility as a lower total dose reduces this risk, or we need to protect the kidneys and other organs.

**Intravenous cyclophosphamide will not be prescribed if:**

- you are pregnant or breastfeeding;
- you have previously had a bad reaction to cyclophosphamide.

## Before your cyclophosphamide treatment, tell your doctor:

- If you are allergic to cyclophosphamide;
- If you are pregnant, trying for a baby or likely to want to have a baby in the future;
- If you are breastfeeding;
- If you have chicken-pox, shingles, other infections or are feeling unwell;
- If you are taking any other medicines or herbal remedies, including medicines purchased over the counter from the chemist;
- If you need any vaccinations in the near future, as some of them should **not** be given at the same time as cyclophosphamide.

## When and how do I receive cyclophosphamide?

You will be given cyclophosphamide as an outpatient, by intravenous injection (into a vein), after having fluid via a drip (intravenous) for 2-4 hours. The dose of cyclophosphamide is calculated taking into account your age, weight and kidney function.

You should drink plenty of water throughout the day before and after the treatment. You will need to empty your bladder (go for a wee) more often to avoid bladder irritation or soreness. Occasionally, patients feel sick after the treatment and are offered anti-sickness medicine before treatment.

For SLE and vasculitis, an injection of cyclophosphamide is given every 2 weeks (until three injections have been given) and then one injection every 3 weeks until the disease is under control, usually up to 3 months. No more than 6 months of treatment is given for SLE or vasculitis.

## What are the possible side effects of cyclophosphamide?

As with all medication, side effects are possible but will not affect everyone. However, you will be given other medicines to take home to prevent potential side effects of cyclophosphamide:

- The most common side effect is feeling sick and sometimes being sick. This may start 2-3 hours after treatment and last for up to 24 hours. You will be offered effective anti-sickness medication to take if you need it.

- **Co-trimoxazole (Septrin)** is an antibiotic. Your immune system doesn’t work so well with cyclophosphamide so you are more likely to get infections. Co-trimoxazole is used to prevent a particular chest infection known as PCP (Pneumocystis jirovecii). The usual dose is one 480mg tablet, three times a week (Mondays, Wednesdays and Fridays), although some patients with Wegener’s disease will be prescribed this daily. It may be taken on an empty stomach or with food.

The dose of co-trimoxazole is very small so you are not likely to have any side effects, however the following may occur:

- Stomach upsets, including feeling sick and diarrhoea – if this happens try taking the tablet after food
- Skin rash

**If you are allergic to co-trimoxazole please inform the doctor.**

- **Nystatin suspension**, an antifungal. This mouthwash helps to prevent infections occurring in your mouth. The usual dose is 1ml (as marked on the dropper), four times a day. Rinse the 1ml around the mouth and then hold in the mouth for a few minutes before swallowing - use after food. Avoid drinks for one hour after using the mouthwash. Side effects are rare.
- **Omeprazole or Lansoprazole.** These decrease the amount of acid in the stomach. Drugs that suppress the immune system, like the high doses of steroids used with cyclophosphamide, can make you more likely to suffer with stomach pains and stomach ulcers. These medications help prevent irritation and damage. Omeprazole is usually given as a 20mg capsule once a day. Lansoprazole is dispersible (dissolves in water) and is given if you have problems swallowing capsules. The usual dose is 30mg once a day. These medications are generally well tolerated.

## Other rare side effects you need to be aware of include:

- Irritation of the bladder. This is why it is important to drink lots of fluid and empty the bladder often. You will be advised on how much to drink 24 hours before the start of treatment and the day after treatment. Tell the doctor if you find it painful or difficult when passing urine after having your treatment.

- The bone marrow (the spongy part in the middle of bones) makes blood cells. These cells fight infections and also carry oxygen round our body. Cyclophosphamide can stop the bone marrow making these cells. It is very important that you have your blood count checked (by a blood test) when you are asked to. Tell your doctor if you notice any unusual bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, or bleeding gums. You may become anaemic (low red blood cells), which may make you feel breathless and tired. Let your doctor know if you suffer from any of these symptoms.

- Cyclophosphamide can affect the way that your liver works. This usually goes back to normal when your treatment is finished. This is very unlikely to cause you any harm, but your doctor will check this carefully by taking blood tests.

- Mouth sores can occur. Use soft toothbrushes, look after your mouth and make sure you have regular six monthly dental check ups.

- You will be more at risk of blood clots so tell your doctor immediately if you feel short of breath or notice swollen legs either during or shortly after treatment.

- You may suffer with headaches.

- Your hair may get thinner, but this is rare. This usually starts 2-4 weeks after the first dose of cyclophosphamide, although it may occur earlier. Usually your hair will start to grow again within a few weeks at the end of treatment. Perms or hair dyes may make hair weaker for the first few months after treatment, so wait a few months if you can.
- Allergic reactions sometimes occur during the treatment. These could be flushing; feeling wheezy and your face may swell; your blood pressure may drop and your heart may feel like it's racing. A doctor will be available during your treatment should you develop any of these symptoms. You may also feel dizzy, have a strange taste and a feeling of having a blocked nose when the infusion is being given. If you notice these, the drip can be slowed down to stop these feelings.
- Rarely, discolouration of the skin has occurred, usually affecting the palms and nails of the hands and the soles of the feet. Another rare side effect is thickening of the lining of the lungs if this happens you may feel breathless.

**Please let your kidney doctor know if you suffer from these or any other unwanted effects during or after treatment with cyclophosphamide.**

After taking the drug for many years, there is a very small risk of developing cancer, however, giving the drug intravenously greatly reduces this risk as a smaller dose is given.

To reduce this risk, avoid sunbathing and when you go out in the sun, always use a sun block to reduce the risk of skin cancers. Women should go for regular smear tests. Following the usual screening programmes for breast and prostrate cancer is recommended. These cancers are not as serious if they are noticed early.

## Infections

Cyclophosphamide can cause your bone marrow to make less white blood cells which fight infection. This can make you more likely to suffer from infections. This effect may show 7 days after having cyclophosphamide, with your resistance to infection usually reaching its lowest point after 10-14 days. Your blood cells will then increase steadily, and will usually have returned to normal levels before your next dose of cyclophosphamide is due. Occasionally, it may be necessary to delay your next dose if the white blood count (WBC) is still low, or you may receive a smaller dose.

Please avoid any unnecessary contact with people known to have infections. Whilst having a course of IV cyclophosphamide treatment, you should tell us if you have any symptoms, such as high temperature (fever), cough, sore throat, burning pain on passing urine, and let us or your GP know early if you start to feel generally unwell. If you see your GP or come to the Accident & Emergency department, remember to say that you are having cyclophosphamide injections.

## Do I need any special checks while on cyclophosphamide?

You will have a physical examination and blood tests before starting the first treatment and then more blood tests after each dose (usually 10 days after a dose). Your results will be reviewed in clinic when you should see a consultant.

## Can I take other medicines along with cyclophosphamide?

You should discuss any new medications with your kidney doctor before starting them, and you should also tell any other doctor treating you that you are taking cyclophosphamide.

- **Do not** take any ‘over-the-counter’ medicines or herbal remedies without first discussing it with your kidney doctor or pharmacist.

- If you are taking **phenytoin** for epilepsy, cyclophosphamide may possibly reduce its absorption, which could lead to reduced control of fits.

- **Avoid** grapefruit juice whilst you are having cyclophosphamide

- If you take a drug called **Clozapine**, tell your doctor - this may give you more side effects if you have the two drugs.

- Some tablets taken to control blood sugars in diabetes may work more effectively with cyclophosphamide, which may increase the risk of suffering from low blood sugars.

## Can I drink alcohol while taking cyclophosphamide?

Yes, in moderation, although alcohol can increase the risk of feeling sick. Follow the recommended safe limits for alcohol of one or two units a day, maximum weekly limit of 14 for women and 14 for men.

## What if I am thinking of having a baby?

Cyclophosphamide is known to be damaging to an unborn child and **must not** be given during pregnancy unless there are exceptional conditions. Pregnancy is not recommended for 12 months after finishing cyclophosphamide treatment, and some form of contraception must be used to prevent this. Men should use contraception for 12 months after finishing a course of cyclophosphamide.

## What about breastfeeding?

Cyclophosphamide is excreted in human breast milk. Therefore, breastfeeding is **not advised** in mothers receiving cyclophosphamide.

## Effects on fertility

Women treated with cyclophosphamide may develop infertility and an early menopause, although this risk increases with increasing age of the patient as well as total treatment dose. Generally patients older than 30-35 years at the time of treatment are more likely to develop an early menopause than younger patients. Menstruation (period) usually returns within one year of stopping cyclophosphamide treatment. If you haven't finished your family you can have an injection once a month to try to prevent you from stopping your periods.

In men, a reduced sperm count develops in relation to the total dose of cyclophosphamide administered. In other words, the more cyclophosphamide you have the more likely you are to have a low sperm count. In many cases this is reversible within one year of completion of the therapy. Occasionally, however, particularly after high doses of cyclophosphamide, sterility is permanent. As a result, sperm banking prior to therapy is recommended. Cyclophosphamide can also result in some foetal (baby in the womb) abnormalities, if you conceive during treatment. Males are therefore advised to take contraceptive precautions throughout treatment and for 12 months after.

## Vaccinations

A vaccine is an injection to prevent you getting a disease. You should **NOT** be vaccinated with some vaccines whilst receiving cyclophosphamide. The nurses or doctor in clinic will be able to tell you which vaccines you can't have.

## What if I have any questions?

If you have any questions or concerns, please speak to a member of the nursing team.

**Please use this space to write down any questions you wish to ask:**

## Further information

If you would like any further information about cyclophosphamide, or if you have any questions or concerns about your treatment, you should discuss this with your consultant, the ward 6b manager or renal pharmacist.

**Dr B Thompson, Renal Consultant** (or other renal consultant)
Renal Ward 6b, Lister Hospital ☎ 01438 284164

**Sister Angela Bernard, Ward 6b Manager**
Renal Ward 6b, Lister Hospital ☎ 01438 284777

**Clare Morlidge, Renal Pharmacist**
Pharmacy Department, Lister Hospital ☎ 01438 284677

## Additional Information

See web site: **www.cancerbackup.org.uk**
(This information relates to the use of cyclophosphamide in cancer)

**Reference -** This leaflet has been adapted from a patient information leaflet produced by Addenbrookes Hospital, Cambridge.

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