

# Cyclophosphamide

Information for patients



Cardio-Respiratory  
Service

This leaflet contains information about Cyclophosphamide to treat Interstitial Lung Disease (ILD) and pulmonary vasculitis (such as Wegener's Granulomatosis). This leaflet will give you more information about this medication.

**My condition is:** .....

**You will normally be under the care of:**

*Dr Beirne, Dr Boland or Dr Sutherland*

If you need to get in touch with one of the doctors or the specialist nurses, their contact numbers are:

Dr Beirne's, Dr Boland and Dr Sutherland's Secretary:  
**0113 206 5113**

Specialist Nurses:  
**0113 206 7120**

## Appointments for cyclophosphamide and blood tests

Infusion Number	Date of Appointment	Blood test after infusion	Blood test before next infusion

## Information about cyclophosphamide

Cyclophosphamide is used to treat a number of different types of Interstitial Lung Disease (ILD) and pulmonary vasculitis.

### *Examples of interstitial lung diseases include:*

- Non-specific Interstitial Pneumonitis (NSIP).
- Hypersensitivity Pneumonitis.
- Connective tissue disease associated ILD (CTD-ILD) (e.g. ILD in Rheumatoid disease, Lupus, Polymyositis/ Dermatomyositis, Mixed Connective Tissue Disease, Sjögren's, Scleroderma).
- Cryptogenic Organising Pneumonia (COP).
- Acute Interstitial Pneumonitis (AIP).
- Lymphoid Interstitial Pneumonitis.

### *This leaflet tells you:*

- how the medicine works
- how it should be given
- whether there are any side effects

Please also read the leaflet called *Unlicensed Medicines: Information for Patients*.

## Why have I been given this leaflet?

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with the treatment.

For most medicines, information is provided by the manufacturer in the medicine package. This medicine does not have a licence for use for interstitial lung disease and pulmonary vasculitis, so the leaflet in the medicine package doesn't tell you everything you need to know. We have written this leaflet to give you some extra information.

## **So this medicine does not have a licence. What does this mean?**

The leaflet called *Unlicensed Medicines: Information for Patients* tells you more about medicine licensing regulations. It also tells you why unlicensed medicines are sometimes used.

## **Why does cyclophosphamide not have a licence?**

Sometimes a medicine has been licensed for a certain use and later use shows that it works for a different illness. The manufacturer can choose whether they apply to the Government to have the more recent information added to the licence. This costs a lot of money so sometimes the manufacturer decides it is not worth their while.

Cyclophosphamide is made by the manufacturer for certain types of cancers. However it is also useful in the treatment of interstitial lung disease and pulmonary vasculitis.

Remember that your doctor will have thought carefully about which medicine is best for your condition and will have discussed this treatment at the Multi-Disciplinary Team meeting.

## **What is cyclophosphamide and how does it work?**

Cyclophosphamide is a medicine that reduces the strength of the immune system (the body's own defence system) and may reduce the inflammation and scarring of the lung tissue. Cyclophosphamide is often prescribed along with steroid tablets such as prednisolone or a steroid infusion such as methylprednisolone. It does not work immediately and may take up to six weeks or more to produce an effect.

## **How will cyclophosphamide be given?**

Cyclophosphamide will be given as an intravenous infusion (through a drip into a vein), and your dose will depend on your height and weight and may change depending on how you respond to treatment. You will need to come to the Respiratory Day Unit at St James's Hospital, or the Day Unit at Chapel Allerton Hospital, for a few hours each time you have an infusion.

Most patients will be given an infusion every three to four weeks for a total of six infusions. After this time, your doctor will assess your response and decide whether to continue or to change your treatment.

## **When should cyclophosphamide not be used?**

- You should not receive this medicine if you have previously had an adverse reaction to cyclophosphamide, or have a history of haemorrhagic cystitis, liver disease or cancer, or if you take any other medicines that affect the immune system.

- Cyclophosphamide can reduce fertility in both men and women and so for young patients, it is used only with caution. The effect may be reversible if you stop taking cyclophosphamide. Women must not receive cyclophosphamide if they are pregnant or breastfeeding. Whilst taking cyclophosphamide and for three months (although preferably for six months) after finishing your treatment, both men and women must take contraceptive precautions. If you are planning a family, or if you become pregnant while receiving cyclophosphamide, you should discuss this with your doctor as soon as possible.

**Cyclophosphamide can cause serious birth defects.**

**Tell your doctor if you are planning a baby or if you could be pregnant**

- Take with extra care if you have kidney disease, or are older than 75 years of age.

**Please tell your doctor if you have any of the conditions listed in the manufacturers leaflet.**

## **Are there any side-effects?**

Most medicines cause side-effects. Cyclophosphamide can sometimes cause a feeling of sickness. Only contact the doctor if this carries on for more than a few days or makes you feel worse.

Taking cyclophosphamide can affect the blood count (one of the effects is that fewer blood cells are made). Your doctor will arrange for you to have a blood test before you start treatment and then regular tests whilst you are receiving treatment with cyclophosphamide. This will check how well your bone marrow is working.

Possible signs of bone marrow damage are anaemia, regularly catching infections, and bruising and bleeding easily. If this happens, you must tell your doctor immediately.

One very important side-effect of cyclophosphamide is inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If this occurs you may notice blood in your urine and you must report this to your doctor immediately. To reduce the risk of this happening, you should increase the number of non-alcoholic drinks each day to the equivalent of 8-10 glasses of water. You will be prescribed a medicine called mesna along with cyclophosphamide to reduce the risk of cystitis. Mesna is taken as a tablet two hours before your cyclophosphamide infusion, then again two and six hours after the infusion.

There is a slightly increased risk of certain types of cancer with cyclophosphamide and your doctor should explain this risk before starting treatment.

Other possible side-effects are loss of hair, mouth ulcers, and irregular menstrual periods. If you develop these or any other new symptoms after starting cyclophosphamide, you should tell your doctor as soon as possible.

**If any of these symptoms are severe, you should see your doctor immediately.**

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should not continue cyclophosphamide and see your doctor immediately as you may need special treatment. This is because chickenpox

and shingles can be severe in people on treatment such as cyclophosphamide which has effects on the immune system. You may require treatment for this.

Everyone reacts differently to medicines. You may have some side-effects or none at all.

## **Will cyclophosphamide affect any other medicines?**

Tell your doctor or pharmacist about all the other medicines you take. This includes any medicines you have had prescribed by another doctor as well as medicines bought from a pharmacy or supermarket and any herbal remedies.

Whenever you are prescribed a new medicine, or want to buy a medicine e.g. from a pharmacy or supermarket, it is important that you tell the doctor or pharmacist about all the medicines that you take, including cyclophosphamide. You should also tell your dentist when you see him/her.

## **Can I drink alcohol while taking cyclophosphamide?**

Yes, it safe to drink alcohol while you are receiving cyclophosphamide treatment, however large quantities of alcohol should be avoided. It is recommended that you do not exceed the national guidelines. These are two units for men and women. One pint of beer is two units; one pub measure of a spirit (25ml) is one unit; and one pub measure of wine (125ml) is one unit.

## Vaccinations

Your doctor or nurse should not offer you any immunisation injections that have any of the 'live' vaccines such as MMR and yellow fever. Pneumococcal (Pneumovax® II) and yearly flu vaccines are safe and recommended.

## Where do I get my next supply?

You will be given dates for when you need to come to the hospital for your next infusion.

## Why do I need to agree to receive this medicine?

Your written consent should be obtained before prescribing any medicine. This leaflet has explained that cyclophosphamide does not have a licence for use in interstitial lung disease and pulmonary vasculitis, and provided information about possible side-effects. Please ask questions if you need more information.

You will be asked to say whether or not you want to receive this medicine. If you agree, but later decide that you don't want to receive cyclophosphamide after all, that is fine. Please tell your doctor.

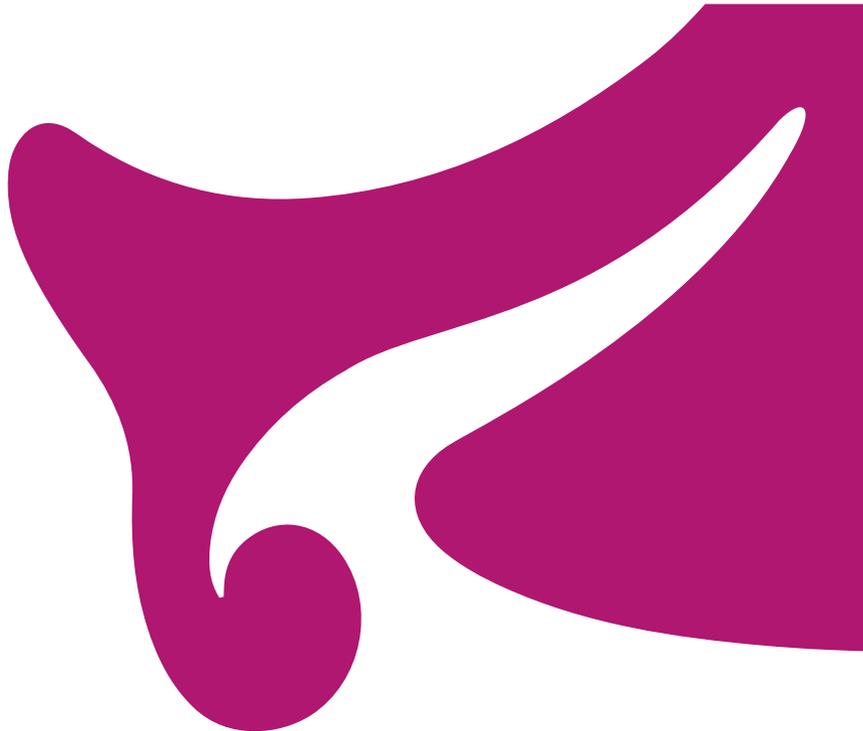
If you have any further questions, please contact your doctor or the specialist nurses, by ringing the telephone numbers on page two.

## How can I find out more?

Your agreement should be obtained before prescribing any medicine.

This leaflet has been written to provide general information about cyclophosphamide. If you have any further questions or concerns, please speak your doctor or pharmacist.

*Please use this page to note down any questions you may have.*



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***Your views matter***



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