

# Cyclophosphamide

Monitoring and dosage records for respiratory patients with interstitial lung disease



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**This leaflet only applies to the use of cyclophosphamide in the management of autoimmune conditions and does not provide advice on the use of cyclophosphamide in patients other conditions.**

## **What is cyclophosphamide and why have I been prescribed it?**

A number of different respiratory conditions are autoimmune disorders. This means the condition and the symptoms associated with it are caused by your immune system attacking your body.

Cyclophosphamide is a medication which suppresses, or dampens down, the body's immune system and is used in a lot of different autoimmune conditions.

Although cyclophosphamide is marketed for the management of certain types of cancer it is often used in autoimmune conditions, such as interstitial lung disease and sarcoidosis, which are **not cancer** at a lower dose.

The information leaflet supplied with cyclophosphamide normally refers to it as an anti-cancer, or anti-tumour, medication without mentioning its use in other conditions which can sometimes be confusing. If you are unsure why you are taking cyclophosphamide you should discuss this with your doctor, specialist nurse or pharmacist.

By suppressing the immune system cyclophosphamide can help manage the symptoms of an autoimmune condition. If cyclophosphamide is being used with a corticosteroid, such as prednisolone, it can also allow the dose of steroids to be reduced and in some cases may allow the steroids to be withdrawn altogether. Because of this it is sometimes also called a 'steroid sparing agent'.

## What you must ensure before taking cyclophosphamide

Cyclophosphamide can have an effect on fertility in both men and women and this may continue after stopping treatment. If you think this may be a problem, for example if you are planning on having children in the future, you should discuss this with your doctor before starting treatment.

**In pre-menopausal women cyclophosphamide can cause irregular menstrual cycles and may cause an early menopause and infertility. If considering cyclophosphamide in pre-menopausal women it is very important to discuss the risks of this and any treatments which could help reduce this.**

Cyclophosphamide should not be used if you think you may be, or are planning on becoming pregnant or are breastfeeding.

## How to take cyclophosphamide

The three main ways of taking cyclophosphamide are;

- Low dose of tablets - usually taken once a day,
- High dose of tablets taken less often - usually once a week or once a fortnight,
- By intravenous infusion - every few weeks (typically at intervals of two – four weeks).

The person prescribing cyclophosphamide will estimate a dose based on your age, weight and kidney function. This may change according to your response to treatment.

Cyclophosphamide tablets should be taken one hour before food or on an empty stomach either in the morning or early afternoon.

The tablets should be taken with plenty of water and should be swallowed whole (not chewed or crushed).

If you miss a dose you should not 'double up'. Take the next dose at the normal time and completely omit the missed dose. If you miss a few doses (two or more) then contact your doctor for advice on what to do next. If you can't contact them straight away, for example if it's a weekend or you are on holiday, then don't worry and let them know when you can.

### **Getting the most from your treatment with cyclophosphamide**

Cyclophosphamide does not work immediately and it can take weeks or a few months before any benefits are noticed. You should take cyclophosphamide as advised by your doctor and let them know if you think you might be experiencing any side-effects or problems which concern you.

You must ensure you do not run out of medication. It is important to realise that it can sometimes take a few days to get a prescription to you. It is a good idea to give about a weeks' notice before you run out.

### **Does cyclophosphamide interact with other medication?**

Cyclophosphamide can increase the blood glucose lowering effect of some oral anti-diabetic medications. If you are taking tablets to manage diabetes you should let the person prescribing cyclophosphamide know.

You should check with the prescriber or pharmacist if any medications can interact with your cyclophosphamide, including any medicines you can buy over the counter.

Do not take herbal remedies without discussing this first with your doctor or pharmacist.

## **What about immunisations?**

If you are taking cyclophosphamide, it is recommended that you should not normally receive 'live' vaccines. Your doctor will discuss the possible risks and benefits of any immunisations you may be offered and should explain these to you. Before having any immunisations it is a good idea to remind the person prescribing them that you are on cyclophosphamide.

Pneumovax, which is used to provide protection against some forms of pneumonia, and the yearly flu vaccines are safe and recommended.

## **Can cyclophosphamide cause side-effects?**

Along with their useful effects all medicines can cause unwanted side effects and some are more common than others. This is not the full list of possible side-effects so please also refer to the patient information leaflet supplied with your medicine for a complete list.

One very important side-effect of cyclophosphamide is inflammation and bleeding of the bladder wall, called haemorrhagic cystitis. To reduce the risk of this happening you should drink 8 – 10 glasses (i.e. 2 – 3 litres) of water or non-alcoholic drinks each day. If you notice any blood in your urine then please contact your doctor immediately for advice.

Cyclophosphamide may cause hair loss/thinning which normally returns to normal even if treatment continues. You should avoid perms or hair dyes for the first few months as your hair will be weaker than normal.

Cyclophosphamide can very rarely cause damage to the heart and this may be permanent. If you breathing worsens during treatment or you develop any swelling of the ankles you should let the team looking after you know so they can provide advice.

Cyclophosphamide can cause a sore-mouth (mucositis), oral ulcers and diarrhoea. If these occur you should contact the team looking after you.

Common side-effects can include; feeling sick and losing your appetite following treatment. Nasal stuffiness and a metallic taste in your mouth.

**Although uncommon if any of the following symptoms develop you should contact your doctor or specialist nurse for advice:**

- Flushing and swelling of the face, wheezing and difficulty in breathing, increased heart rate or decreased blood pressure.
- Redness of the skin or a skin rash, fever, shivering or chills,
- Feeling nauseous or being sick,
- Changes in the amount of urine passed or the colour of the urine,
- Unexpected bleeding or bruising,
- Severe diarrhoea or abdominal pain,
- Jaundice (yellowing of the eyes or skin),
- Blistering and/or peeling of the skin,

## **What else do I need to know about cyclophosphamide treatment?**

As an immunosuppressant cyclophosphamide can make you more likely to develop infection. The clinic or your GP should regularly monitor your blood to check that treatment does not excessively reduce your white cells (which are an important part of the immune system). You should contact your doctor straight away if you notice any signs of infection such as a sore throat, chest cough or fever.

Whilst on treatment you should avoid unnecessary exposure to things which can cause infections, this includes avoiding unpasteurised milk or cheese, uncooked meat and raw vegetables. Ensuring appropriate oral and hand hygiene also helps to reduce the risk of infections.

Chickenpox or shingles can be severe in patients on immunosuppressant treatments. If you have not had chickenpox and you come into contact with someone who has either chickenpox or shingles you should stop taking cyclophosphamide and contact your doctor for advice. If they think you may be at risk they will be able to prescribe antiviral treatments to manage this.

Cyclophosphamide might increase the risk of some types of cancers and your doctor should explain this risk before starting treatment.

As with other immunosuppressant medications it is good advice to use appropriate skin protection, such as using sun cream and avoiding excess sun exposure whilst receiving treatment.

## What monitoring is required when I am taking cyclophosphamide?

Before starting treatment the person prescribing cyclophosphamide will arrange a blood sample to assess your liver and kidney function to check if they need to change the starting dose or monitor you more closely. They will also arrange a blood sample called a **Full Blood Count** or **FBC** which looks at the number of white cells, platelets and red cells you have.

Before starting patient on immunosuppressive medications it is normal to send a blood test to rule out HIV, hepatitis or tuberculosis infections. Your doctor will discuss this with you before requesting the tests, if you have any objections you should let them know.

Because cyclophosphamide can affect the production of blood cells, and can also sometimes cause liver or kidney problems, the clinic or your GP will arrange for you to have regular blood checks whilst on cyclophosphamide.

It is important to have your blood test carried out regularly to identify any changes. Cyclophosphamide cannot be prescribed unless you are able to have regular checks.

It takes a day or two for the results of your blood tests to come back and these will be checked by the doctor taking them who will get in touch if there are any problems.



## Unlicensed medicines

Cyclophosphamide is marketed for use in the management of certain types of cancer and when used in this situation it is referred to as being used within its product license.

Other conditions are not included in the product license and this is generally because the manufacturer has not applied to have the condition added. In these cases the product is said to be used 'off-license' or 'off-label' and there will be no reference to the condition in the patient information leaflet (PIL) supplied with the medicine.

If the medicine is being used off-license than the prescriber will explain the expected risks and benefits before starting treatment.

### Medicines labelled as "hazardous waste"

As with all medicines cyclophosphamide should be;

- Kept out of the reach and sight of children.
- Taken as directed by your doctor or pharmacist and should only be taken by the patient named on the label.

In general all immunosuppressant medications are classified as 'hazardous waste' and so in addition to this general advice you should ensure any unused cyclophosphamide tablets are safely disposed of.

The best way to dispose of hazardous waste would be to return it to a pharmacy in its original container. You **should not** dispose of them in the household waste or via the sink or toilet.

**This booklet belongs to:**

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Date of Birth: \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_

NHS Number: \_\_\_\_\_

Condition requiring treatment with cyclophosphamide: \_ \_ \_ \_

Consultant/Specialist: \_\_\_\_\_

Who to contact for routine advice on cyclophosphamide: \_\_ \_\_

On telephone number: \_\_\_\_\_

Date of dose advice	Dose in mg per day

Other notes or comments:

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Name: \_\_\_\_\_

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Date	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	Hb	
Hb Varies (g/dL)																					
MCV 84 – 98fL																					
White blood cells Normally <b>4</b> – 11 x 10 <sup>6</sup> /L																					
Neutrophils Normally <b>2</b> – 7.5 x 10 <sup>6</sup> /L																					
Lymphocytes Normally <b>1.5</b> - 4 x 10 <sup>6</sup> /L																					
Platelets Normally <b>150</b> – 400 x 10 <sup>9</sup> /L																					
Bilirubin Normally 3 - <b>17</b> µmol/L																					
AST or ALT Normally 3 – <b>35</b> iu/L																					
Alkaline phosphatase Normally 30 – <b>130</b> iu/L																					
Creatinine Varies (µmol/L)																					
Urea Normally <6.7mmol/L																					
eGFR Varies (mL/min/1.73m <sup>2</sup> )																					

## What the terms mean

**Hb:** a measure of the amount of haemoglobin (the oxygen carrying part of red blood).

**MCV:** a measure of the average size of the red blood cells. Large or small cells (bigger than 98fL or smaller than 84fL) might suggest certain types of anaemia.

**Neutrophils** and **lymphocytes:** are types of white blood cells which attack and kill micro-organisms (germs). They are very important in preventing infection and the number will increase quickly to combat an infection. A low count of less than  $2 \times 10^6/L$  **neutrophils** or less than  $1.5 \times 10^6/L$  **lymphocytes** may indicate that cyclophosphamide is affecting the production of blood cells.

**Platelets:** a component of blood that is involved in normal clotting. A low count of less than  $150 \times 10^6/L$  may indicate that cyclophosphamide is affecting the production of blood cells.

**Bilirubin:** is a waste product that is normally removed by the liver and gives the dark colour to faeces (stool). In some cases when the liver is working less efficiently this builds up in the blood and can cause the eyes and skin to be tinged yellow – this is called jaundice. Jaundice is also associated with paler stools and darker urine.

**ALT** and **alkaline phosphatase:** are enzymes normally present in the liver that are released into the blood stream when the liver is damaged. High levels of either enzyme in the blood may indicate that cyclophosphamide is affecting the liver.

**Urea** and **Creatinine:** are substances normally cleared from the blood by the kidneys. Increased blood levels of either may indicate that cyclophosphamide is affecting the kidneys.

**eGFR:** is an estimate of how well the kidneys are functioning and helps when looking at the urea and creatinine results.

**Other notes or comments:**

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NHS Constitution. Information on your rights and responsibilities.  
Available at [www.nhs.uk/aboutnhs/constitution](http://www.nhs.uk/aboutnhs/constitution)

**PATIENT  
APPROVED** 

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[www.nbt.nhs.uk](http://www.nbt.nhs.uk)

If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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