

## Patient information

# Cyclophosphamide for Non-oncology and Auto-immune Conditions

## Rheumatology and Nephrology Specialties

### Cyclophosphamide for the treatment of non-oncology and auto-immune conditions

Your consultant / doctor has advised you to have cyclophosphamide for the treatment of a non-oncology (non-cancerous) or auto-immune conditions. This may be vasculitis, SLE, scleroderma, myositis, Bechet's syndrome, or a kidney problem such as glomerulonephritis for example. Your doctor and specialist nurse will explain in more detail the reason why you are having this treatment and how it will treat this condition.

### What is Cyclophosphamide?

Cyclophosphamide is a "cytotoxic agent" which means it has a toxic effect on many types of cells ("good" cells as well as "bad"). Cyclophosphamide is a white powder, which dissolves to form a colourless liquid.

### What are the benefits of having cyclophosphamide?

The medicine is very effective in the treatment of a wide range of conditions and auto immune diseases because it has significant ability to suppress the immune system (the body's own defence system).

### What are the risks of having cyclophosphamide?

Each person's reaction to cyclophosphamide is different. Some people have few side effects, while others may experience more. Some of these side effects can be life threatening, particularly infections.

### The side effects experienced listed will not affect everyone.

- **Lowered resistance to infection (neutropenia).**

Cyclophosphamide can reduce the number of white blood cells produced by the bone marrow, making you more prone to infections which a person's intact immune system would normally be able to fight off.

It does not enhance a person's susceptibility to the common cold. It does however, heighten the risk of more serious infections, including tuberculosis, fungal infections (for example thrush, and pneumocystis jiroveci pneumoni (PJP), and serious viral infections (for example "shingles and warts" ).

This effect can begin seven days after treatment has been given and your resistance to infection usually reaches its lowest point ten to fourteen days after treatment has been given.

The number of white cells will then increase steadily and usually return to normal before your next infusion is due. An antibiotic, to be taken daily or every other day will be given to try to prevent the more serious infection "PCP".

### **Bone Marrow Suppression**

The bone marrow is the organ that makes red blood cells (which carry oxygen), and white blood cells (which fight infection), and platelets (which help the blood clot).

Nearly all patients treated with cyclophosphamide experience some suppression of the bone marrow's ability to produce these vital elements whilst having the infusions and may experience tiredness and breathlessness due to a drop in red blood cells (anaemia). You may bruise more easily and experience nose bleeds and bleeding gums after brushing your teeth.

When cyclophosphamide is given intravenously the blood count reaches its low point ("nadir") between seven to fourteen days after administration. Therefore, a blood test will be done approximately ten days after every infusion to monitor this.

### **Feeling sick (nausea) and being sick (vomiting)**

This may begin two to three hours after the infusion and may last for up to 48 hours. Anti-sickness medication will be routinely prescribed to help with this.

### **Tiredness, loss of appetite and weight loss**

A dietician at the hospital can give advice and tips on boosting appetite, coping with eating

difficulties and maintaining weight. Your nurse will be able to arrange this if required.

### **Irritation of the bladder lining**

Cyclophosphamide may cause a variable amount of bleeding from the bladder, known as "haemorrhagic cystitis". This is a rare occurrence when cyclophosphamide is given intravenously with mesna tablets. These tablets will need to be taken on the day of the infusion along with adequate fluids to drink. This also helps prevent bladder cancer as detailed below.

### **Hair Thinning/Loss**

You may develop a marked, reversible thinning of your hair two to four weeks after the first dose of cyclophosphamide. You may also have thinning of eyelashes, eyebrows and other body hair. A very small number of people lose their hair completely. Usually your hair will start to grow back within a few weeks after treatment ends.

## Cancer

There is a very small risk of developing at least two types of cancer; lymphocytic leukaemia and bladder cancer. Whilst it is very likely that you will have regular urine tests it is recommended that you have a 'dip' urine test annually.

There may also be increased risks for other kinds of cancer, but the risks are less. Your doctor will discuss this further with you.

### **Less common side effects:**

Sore mouth and ulcers, taste change, diarrhoea, nail changes, darkening of the skin, pancreatitis, blood clot formation, changes in lung tissue may lead to a cough or breathlessness and changes in the way your heart works (very rare with standard doses) are all less common side effects that are associated with cyclophosphamide. Once the treatment has finished it is expected that these symptoms will subside.

Very rarely your liver and kidney function may be temporarily affected, but it is expected to return to normal when the treatment is finished. This is very unlikely to cause you harm and will be checked with your "nadir" blood test.

### **Additional information**

When the treatment is being given some people have hot flushes, dizziness, a strange taste and a feeling of having a blocked nose.

Tell your doctor about any medicines you are taking, including over-the-counter drugs, complimentary therapies and herbal drugs as some medicines can be harmful to you when you are having Cyclophosphamide.

**Your ability to become pregnant or father a child may be affected by this drug. For women, cyclophosphamide may affect your ability to become pregnant by causing the onset of a premature menopause.**

**For men, there is a risk of the drug causing male sterility, reducing your ability to father a child (there is no effect on potency). It is important to discuss fertility with your doctor before starting treatment.**

It is not advisable to become pregnant or father a child whilst having this treatment as it may harm the developing baby. It is necessary to use effective contraception whilst having the treatment and for at least three months after treatment has ended.

### **What will happen if I decide not to have treatment?**

Your disease will not be controlled. Where there are contraindications, alternative treatment modes will be discussed.

**If you are worried about any of these risks, please speak to your consultant or a member of their team.**

## **Getting ready for your cyclophosphamide infusion.**

- On the day of your infusion please ensure that you drink adequate fluids and take a Mesna tablet two hours before the time of the infusion. The specialist nurse will explain this to you.
- Please leave all cash and valuables at home. The Trust does not accept responsibility for items not handed in for safekeeping.
- On arrival to the ward a small cannula (fine plastic tube) will be inserted into a vein and the infusion takes approximately one hour.
- During the infusion cyclophosphamide can accidentally leak into the skin. This may cause mild discomfort, but cyclophosphamide does not cause inflammation or damage to the skin.
- After the infusion is completed the cannula will be removed and you will be able to go home.

## **Discharge Information**

As a general rule, patients receiving cyclophosphamide should assume that body fluid's are hazardous. Precautions for handling urine should continue for three days after completion of each infusion and faeces for five days.

Male patients are advised to urinate while sitting on the toilet to minimise splashing. Close the toilet lid before flushing to minimise aerosol formation and double-flush the toilet.

**Always wear** strong household gloves when cleaning up any spillages.

**To avoid potential absorption of cyclophosphamide by-products through intimate contact you and your partner should use a condom for a minimum of 48 hours following infusion.**

**You may have a reduced resistance to infection. Please contact your specialist nurse team or infusion unit (see contact details below) if you become unwell or develop:**

- A temperature above 38 'C.
- Coldness or shivering with aching muscles.
- Any unexplained bruising or bleeding.
- Severe diarrhoea.
- Unrelieved shortness of breath.
- Mouth ulcers that stop you eating or drinking.
- Sore throat.
- Pain passing urine.
- Severe headache.

## **Medication**

The nursing staff will advise you about the specific medication to be taken after the infusion and any anti-sickness tablet that you may require.

## **Further Appointments**

The number of infusions of cyclophosphamide you will require depends on the condition being treated. Your future appointments will be clearly explained to you.

## **Feedback**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your Outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

## **Further information**

**For further information please contact relevant department/hospital below**

### **Contact Details**

**Vasculitis Nurse Team:  
Monday – Friday**

**If your treatment is at Broadgreen Hospital:-**

**Vasculitis Advice line  
Tel: 0151 282 6052**

**Lupus Advice Line  
Tel: 0151 282 6047**

**Broadgreen Hospital  
Ward 4 Tel: 0151 282 6758  
Ward 10: 0151 706 2396**

**If your treatment is at Aintree Hospital (Rheumatology):-**

**Vasculitis / Behcet's adviceline  
Tel: 0151 529 8123**

**Rheumatology Nurse advice line  
Tel: 0151 529 3034**

**Aintree Hospital Medical Day Case Unit**  
**Tel: 0151 529 8076**

**If your treatment is at Royal Liverpool Hospital:**

**Immunosuppression (Vasculitis and Lupus Nephritis) Nurse Team**  
**Liverpool and Aintree Hospitals (Nephrology)**  
**Tel 0151 706 3188**

**Royal Liverpool Hospital Secretaries (Nephrology)**  
**Tel: 0151 706 3429**

**Aintree Hospital Secretaries (Nephrology)**  
**Tel: 0151 529 8797**

**Broadgreen Hospital Ward 10**  
**Tel: 0151 706 2396**

**Aintree Hospital Medical Day Case Unit**  
**Tel: 0151 529 8076**

**Out of Hours**  
**NHS 111**  
**Tel: 111**

**Useful Websites:**

**[www.vasculitis-uk.org.uk](http://www.vasculitis-uk.org.uk)**

**[www.lupusuk.org.uk](http://www.lupusuk.org.uk)**

**[www.myositis.org.uk](http://www.myositis.org.uk)**

**[www.nras.org.uk](http://www.nras.org.uk)**

**[www.behcetsuk.org.uk](http://www.behcetsuk.org.uk)**

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