Cyclophosphamide treatment for interstitial lung disease

This leaflet explains about having cyclophosphamide treatment for interstitial lung disease (ILD). It includes information on the benefits, risks, and possible side effects and their management. If you have any further questions or concerns, please speak to a doctor or nurse caring for you.

What is cyclophosphamide and how is it used?
Some interstitial lung diseases are caused by overactivity of the immune system, which causes inflammation in the lungs and leads to irreversible scarring (lung fibrosis). The aim of cyclophosphamide treatment is to reduce the inflammation in order to stop the fibrosis getting worse. It is not able to remove scarring/fibrosis that has already taken place.

Cyclophosphamide is often prescribed along with steroid tablets or a steroid infusion given through a vein. It may take up to six weeks or more before you notice an improvement in your symptoms.

When and how do I take cyclophosphamide?
Cyclophosphamide is given through a drip into a vein. Your doctor will decide on the dosage and the frequency of administration. Cyclophosphamide can be given to you as a ‘day case’ and hospital admission is not required.

What are the risks and possible side effects?
Due to its effect on the immune system, cyclophosphamide can make you more likely to pick up infections. You will need to make sure you have regular blood tests.

Tell your doctor, specialist pharmacist or nurse specialist straight away if you develop any of the following while you are receiving cyclophosphamide:

- a sore throat
- a fever
- any other symptoms of infection
- unexplained bruising or bleeding
- any other new symptoms or anything else that concerns you.

Other risks and possible side effects:

- If you develop chickenpox or shingles, or come into contact with someone who has chickenpox or shingles, please see your doctor as soon as possible. You may need antiviral treatment and your cyclophosphamide may need to be stopped until you are better.
A common side effect of cyclophosphamide is nausea (feeling sick). We may prescribe medicine such as domperidone or ondansetron to help with this.

You may experience blurred vision and dizziness, which could affect your ability to drive or operate heavy machinery. If this is relevant to you, please speak to your doctor or nurse.

Headaches.

Fatigue.

Bladder irritation that may cause blood to appear in your urine (haemorrhagic cystitis). To reduce the risk of this occurring, you should drink three litres of non-alcoholic fluids (such as water) daily, on the day of the treatment and for at least 24 hours afterwards.

You will also be given another medicine called mesna to help to protect the lining of your bladder.

Occasionally cyclophosphamide can cause hair to fall out. Hair will normally start to regrow once the treatment is over, and sometimes even during treatment.

Reduced sperm count. Please discuss this with your doctor before starting the treatment as a referral to a fertility specialist may be required.

Irregular menstrual periods and loss of ovulation. Please discuss this with your doctor before starting the treatment as a referral to a fertility specialist may be required.

There is a slightly increased risk of certain types of cancer, particular bladder cancer, with cyclophosphamide but it will not be recommended for you unless the benefits of treatment are thought to be much greater than the risks. You should discuss this with your doctor.

Tell your doctor immediately if you experience allergic symptoms such as flushing, wheezing, swelling of the face, increased heart rate, decreased blood pressure and breathing difficulties.

Taking other medicines
Some drugs can interact with cyclophosphamide, so speak to your doctor before starting any new medication. If you are treated by anyone other than your usual healthcare team, remember to mention that you are on cyclophosphamide. Do not take over-the-counter medicines or herbal remedies without discussing this first with your doctor, pharmacist or specialist nurse.

Pregnancy and breastfeeding
Cyclophosphamide should not be used if you are pregnant or breastfeeding, as it is harmful to the baby. A pregnancy test may need to be carried out before treatment.

Both men and women must take contraceptive precautions, and will need to continue doing so for six months after treatment is stopped.

If you become pregnant while being treated with cyclophosphamide, you must inform your doctor as soon as possible.

Breastfeeding must be avoided during treatment and for 36 hours after treatment.

Can I have vaccinations?
Live vaccines – such as yellow fever, shingles, bacillus Calmette-Guerin (BCG), and measles, mumps and rubella (MMR) vaccinations – should be avoided while being treated with cyclophosphamide. If you are offered the shingles vaccination, it is best to have it before starting cyclophosphamide treatment.
The pneumonia and yearly flu vaccines are safe and recommended.

If you have any questions or concerns about vaccinations, please speak to a doctor, specialist pharmacist or nurse specialist treating you.

**What to expect after your cyclophosphamide infusion**
You may feel tired and nauseous following the infusion, therefore it is important to take it easy and rest. Ensure you take your domperidone or ondansetron that is prescribed for nausea if you need to. To reduce the risk of haemorrhagic cystitis, you should drink three litres of non-alcoholic fluids (such as water) daily, on the day of the treatment and for at least 24 hours afterwards.

**Useful sources of information**

**Contact us**
If you have any questions or concerns about cyclophosphamide, please contact the ILD helpline, t: 020 7188 8635 (Monday to Friday, 9am-5pm).

In the event of an emergency, please see your GP or attend your local emergency department (A&E).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit w: www.guysandstthomas.nhs.uk/leaflets

**Pharmacy Medicines Helpline**
If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.
t: 020 7188 8748, Monday to Friday, 9am to 5pm

**Your comments and concerns**
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

**Language and accessible support services**
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

**NHS 111**
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111 w: 111.nhs.uk
NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy’s and St Thomas’ NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319  e: members@gstt.nhs.uk  w: www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?
We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, w: www.guysandstthomas.nhs.uk/leaflets, or e: patientinformationteam@gstt.nhs.uk