

University College London Hospitals 
NHS Foundation Trust

National Hospital of Neurology and Neurosurgery

Queen Square Centre for Neuromuscular Diseases

Patient information leaflet:
Cyclophosphamide



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Introduction

This booklet discusses the use of cyclophosphamide in inflammatory neuromuscular diseases: what is it, why is it used, how is it taken, the aims and possible side effects related to its use.

The Queen Square Centre for Neuromuscular diseases have produced this leaflet as part of a guideline for patients and healthcare staff on the safe and appropriate use of medication which suppresses the immune system in inflammatory neuromuscular diseases. Content is reviewed and updated every 2 years by Dr Aisling Carr, consultant neurologist.

What is cyclophosphamide?

Cyclophosphamide should help treat your condition. It has been in use for many years and has helped many people. However, as with all drugs some people will have side-effects.

In some conditions where the immune system is overactive cyclophosphamide is used to suppress the immune system (by damaging rapidly multiplying cells) to bring the disease process under control.

Cyclophosphamide is often prescribed along with steroid tablets or steroid injections. Cyclophosphamide doesn't work straight away – it may take six weeks or more before you notice an improvement. You should receive full information about the treatment plan before starting your cyclophosphamide and you may be asked to sign a written consent form.

Why is it used?

Cyclophosphamide helps to achieve long-term control of symptoms due to inflammation in various neuromuscular conditions, such as:

- Vasculitis
- Difficult to treat inflammatory muscle and nerve diseases
- Difficult to treat myasthenia gravis
- Also in some cancer treatments (chemotherapy)

What are the possible side effects?

As with all medications, cyclophosphamide can sometimes cause side effects including:

- Nausea (your doctor may prescribe anti-sickness medication)
- Hair loss – although this is rare in the doses we use for neuromuscular diseases
- Mouth ulcers
- Irregular menstrual periods

Because of its effects on the immune system, cyclophosphamide can make you more likely to pick up infections. It can also make them harder to spot. You should make sure you have repeat blood tests and tell your doctor or neurology nurse specialist straight away if you develop any of the following after starting cyclophosphamide:

- a sore throat,
- fever or any other signs of infection,
- unexplained bruising or bleeding,
- yellowing of the skin or eyes (jaundice),
- any other new symptoms or anything else that concerns you.

You should stop cyclophosphamide and see your doctor immediately and get a prompt blood test if any of these symptoms are severe or if you become very unwell.

You should also see your doctor if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. These infections can be severe in people on cyclophosphamide. You may need antiviral treatment, and you may be advised to stop taking cyclophosphamide until you're better.

One very important side-effect is inflammation and bleeding of the bladder wall (haemorrhagic cystitis). If this happens you may notice blood in your urine and you must see your doctor immediately. To reduce the risk of this happening, you should drink 8–10 glasses (2–3 litres) of non-alcoholic drinks or water a day. You may be prescribed a drug called mesna to try to reduce the risk of cystitis.

Cyclophosphamide can also affect your blood count, which means your body is making fewer blood cells. Because cyclophosphamide can affect the blood and the bladder, your doctor will arrange for you to have a blood and urine test before you start treatment. You will need to have regular blood tests done while taking cyclophosphamide, these will be done either by your GP or in the hospital. The neuromuscular clinical nurse specialist will keep a record of your results.

YOU MUST NOT TAKE CYCLOPHOSPHAMIDE UNLESS YOU'RE HAVING REGULAR BLOOD CHECKS.

There is a slightly increased risk of certain types of cancer, particularly 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 matter with your doctor or nurse specialist.

What can I do to avoid infections?

Try to avoid close contact with people with severe active infections. For advice on avoiding infection from food, visit: <http://www.nhs.uk/conditions/food-poisoning/pages/prevention.aspx>

What vaccinations should I get?

It's usually recommended that you avoid live vaccines, such as yellow fever, if you're on cyclophosphamide. However, sometimes a live vaccine may be necessary – for example, rubella vaccination in women of childbearing age. If you're offered shingles vaccination (Zostavax), you should speak to your neurology team – you may be able to have the shingles vaccine if you're on a low dose.

Pneumococcal vaccine (which gives protection against the commonest cause of pneumonia) and yearly flu vaccines are recommended

Is there an alternative?

Cyclophosphamide is a strong immunosuppressant and therefore there are few other drugs which are as effective. In some situations rituximab is considered as an alternative but is not routinely prescribed in neurology outside vasculitis. Another option may be participating in a clinical trial, if you are suitable you will be approached by your consultant.

What if I choose not to take it?

The medical team will explain the alternatives and the typical outcome in people with your condition if treated or left untreated. If they are happy that you fully understand the implications of your decision your choice will be respected.

How do I take it?

Cyclophosphamide can be taken:

- either through a drip into a vein (intravenous infusion), which will need to be given in hospital typically at 3 week intervals

- or as tablets (either taken as a low dose taken once a day or a larger dose at 3 week intervals). These should be swallowed whole, not chewed, and should be taken with or after food and with plenty of water.

Your doctor will discuss the options with you. The dose will depend on your body weight and may change depending on how you respond to the drug.

It's important to attend for your planned infusions or take the cyclophosphamide tablets as directed (unless you have severe side-effects):

- even if it doesn't seem to be working at first
- even when your symptoms start to improve (to help keep your condition under control).

Can I take other medications with cyclophosphamide?

Some drugs can interact with cyclophosphamide. Check with your doctor or pharmacist before starting any new medications, and remember to mention you're on cyclophosphamide if you're treated by anyone other than your neurology team.

- Don't take over-the-counter preparations or **herbal remedies** without discussing this first with your healthcare team.

Can I drink alcohol while taking cyclophosphamide?

There is no particular reason to avoid alcohol while taking cyclophosphamide.

Is cyclophosphamide safe in pregnancy and breastfeeding?

Cyclophosphamide can reduce fertility in both men and women, though stopping the drug may reverse this effect. You should discuss this with your doctor, preferably before you start the treatment. There may be options available to help you preserve your fertility if this is important to you.

Cyclophosphamide shouldn't be used by pregnant women. **Men and women taking cyclophosphamide must take contraceptive precautions, and need to continue doing so for at least three months after treatment is stopped.** If you're planning a family or if you become pregnant while taking cyclophosphamide, you should discuss this with your doctor as soon as possible.

You shouldn't breastfeed if you're on cyclophosphamide. The drug may pass into the breast milk and could be harmful to your baby.

References

Yates et al. **EULAR/ERA-EDTA recommendations for the management of ANCA-associated vasculitis.** *Ann Rheum Dis* doi:10.1136/annrheumdis-2016-209133

Contact details

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Where can I get more information?

www.wikipedia.org/wiki/cyclophosphamide

www.arthritisresearchuk.org

<http://www.myositis.org.uk/>

<http://www.vasculitis.org.uk/>

Any cyclophosphamide document at www.medicines.org.uk

For further detail please also see the relevant Summaries of Product Characteristics (SPC) document at www.medicines.org.uk

Guillain-Barré & Associated Inflammatory Neuropathies Charity

Tel: 01529469910

<http://www.gaincharity.org.uk/>

British Rheumatological society: Patient information

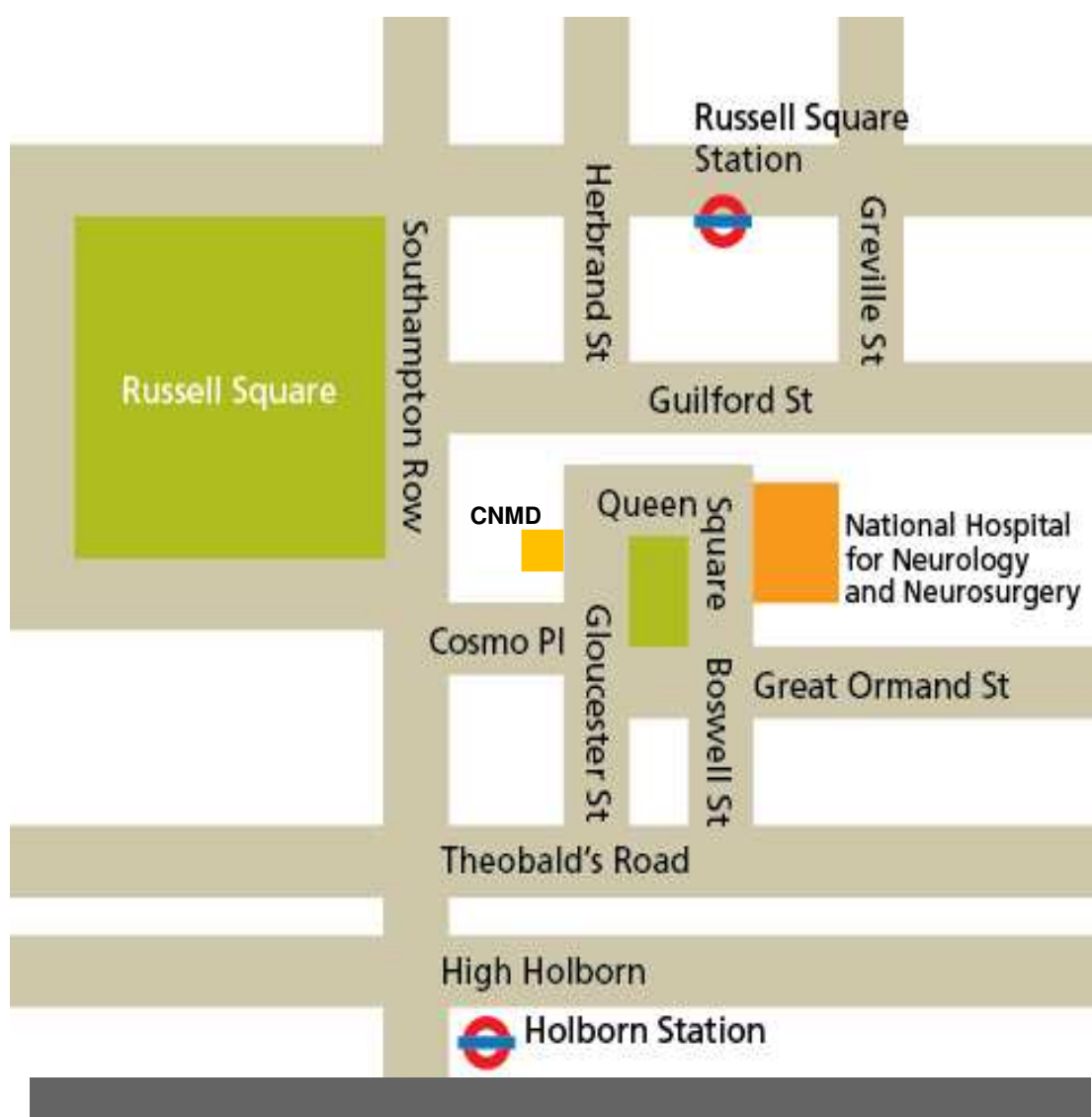
Tel: +44 (0) 20 7842 0900

<http://www.rheumatology.org.uk>

UCLH cannot accept responsibility for information provided by external organisations.

How to find us

Neuromuscular outpatient clinics run across the hospital outpatient departments, please see your appointment letter for further information. The Centre for neuromuscular diseases (CNMD) is based on the ground floor of 8-11 Queen Square, directly across from the main hospital entrance.



Space for notes and questions

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