National Hospital of Neurology and Neurosurgery

Queen Square Centre for Neuromuscular Diseases

Patient information leaflet:

Methotrexate

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Introduction

This booklet discusses the use of methotrexate 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 methotrexate?

Methotrexate 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.

Methotrexate reduces the activity of the body's defence mechanism (immune system), which may be overactive in some conditions. It modifies the underlying disease process to limit or prevent tissue damage and disability, rather than having an immediate effect on symptoms.

Methotrexate is a long-term treatment, so it may be 6–12 weeks before you start to notice the benefits. Unless you have severe side-effects it is important to keep taking methotrexate: even if it doesn't seem to be working at first and even when your symptoms seem to have improves (as this will help to keep the disease under control).

Why is it used?

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

- Myasthenia Gravis
- Inflammatory muscle diseases or myositis (dermatomyositis, polymyositis, overlap myositis)
- Vasculitis
- Other rheumatological and medical conditions like rheumatoid arthritis, lupus (SLE),asthma, allergy, Crohn's Disease, eczema
- In some cancer treatments (usually at much higher doses)
- sarcoidosis

What are the possible side effects?

As with all medications, methotrexate can sometimes cause side effects such as:

- nausea (feeling sick), vomiting, diarrhoea,
- mouth ulcers
- hair loss (usually minor) and skin rashes.

Methotrexate can affect the lungs so you'll have a chest X-ray before starting it. Patients suffering from long-term lung diseases like fibrosis, emphysema or COPD are often not suitable for methotrexate.

It can also affect the blood (causing fewer blood cells to be made) or the liver. You will therefore need to have blood tests before starting methotrexate and at regular intervals while you're taking it. You will have these blood tests taken by your GP or at the hospital. The neuromuscular clinical nurse specialist will keep a record of your results.

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

Is infection a side-effect of methotrexate treatment?

Yes! Because methotrexate affects the immune system, it can make you more likely to develop infections. You should tell your doctor or nurse specialist straight away if you develop any of the following after starting methotrexate:

- 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 methotrexate and see your doctor immediately if any of these symptoms are severe or if you become very unwell. In rare cases, methotrexate causes inflammation of the lung with breathlessness. If this happens to you, see your doctor.

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 methotrexate. You may need antiviral treatment, and you may be advised to stop taking azathioprine until you're better.

Can I do anything to reduce the side-effects of methotrexate?

Yes, most doctors prescribe folic acid tablets to patients who are taking methotrexate as this can reduce the likelihood of side effects. Most doctors advise that it shouldn't be taken on the same day as methotrexate.

You can also try to avoid infections:

- 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
- Vaccinate

What vaccinations should I get?
It's usually recommended that you avoid live vaccines, such as yellow fever, if you're on methotrexate. 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?

There are a number of alternatives to methotrexate with a range of different side-effects. Drugs such as azathioprine and mycophenolate have a similar effect on the immune system as methotrexate and are considered when methotrexate is not well tolerated.

If your disease is not fully controlled by methotrexate then stronger medications, such as cyclophosphamide might be suggested. We have produced patient information leaflets on all these medications.

What will happen 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?

Methotrexate is usually taken in tablet form **once a week** on the same day. The tablets should be swallowed whole and not crushed or chewed.

What dose do I take?

Methotrexate tablets come in two strengths, 2.5 mg and 10 mg. To avoid confusion it's recommended that only the 2.5 mg tablet is used. The two strengths are different sizes but are a very similar colour, so you should always check the dose is correct. In the early stages of a condition it's often treated more aggressively and so the starting dose can range from 7.5–15 mg per week. Your doctor may then increase this dose if it isn't helping your symptoms, but it won't usually go higher than 25 mg weekly.

Alternatively, methotrexate may be given once a week by injection, usually subcutaneous, if there are side-effects with tablets. A subcutaneous injection is given into a layer of fat between the skin and muscle, rather than intravenously which means directly into a vein.

Can I take other medications with methotrexate?

Some drugs can interact with methotrexate. Check with your doctor before starting any new medications, and remember to mention you're on methotrexate 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.
- Some antibiotics can interact with methotrexate – for example**, trimethoprim** and **septrin** should not be taken with methotrexate. If you have an infection that requires antibiotics you may need to stop your methotrexate until you are better and off antibiotics.
- Anti-epileptic medication (**phenytoin**) and anti-asthma medication (**theophylline**) should be avoided as they may increase levels of methotrexate in your blood. However, it's important that you discuss this with your specialist team and that you don't stop any of these medications suddenly.

Can I drink alcohol while taking methotrexate?

You should only drink alcohol in small amounts because alcohol and azathioprine can both affect your liver. It's important not to drink more alcohol than the government recommended safe limits – these state that adults shouldn't drink more than 14 units per week. It's also strongly recommended to have alcohol free days without 'saving units up' to drink all in one go. If you're concerned you should discuss your alcohol intake with your neurology team.

Is methotrexate safe in pregnancy and breastfeeding?

Current guidelines state that methotrexate may harm the baby if taken during pregnancy.

You can still have a successful pregnancy if you stop taking methotrexate in plenty of time before trying for a baby. **Women using this drug should take contraceptive precautions.** After stopping methotrexate you should continue using contraception for at least one month. You should talk to your doctor as soon as possible if you're planning to start a family.

If you become pregnant while taking methotrexate, you should stop taking it and see your doctor as soon as possible.

Previously, there was concern that methotrexate may affect sperm and thus any fertilised egg but it has not been shown to be a problem in research studies. Therefore, current guidelines advise that men do not need to stop taking methotrexate before trying for a baby. You should talk to your neurologist about these matters.

The drug may pass into breast milk and the effects upon your baby are uncertain, so you shouldn't breastfeed if you're on methotrexate.

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References

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Where can I get more information?

www.wikipedia.org/wiki/azathioprine
www.arthritisresearchuk.org
Any azathioprine document at www.medicines.org.uk

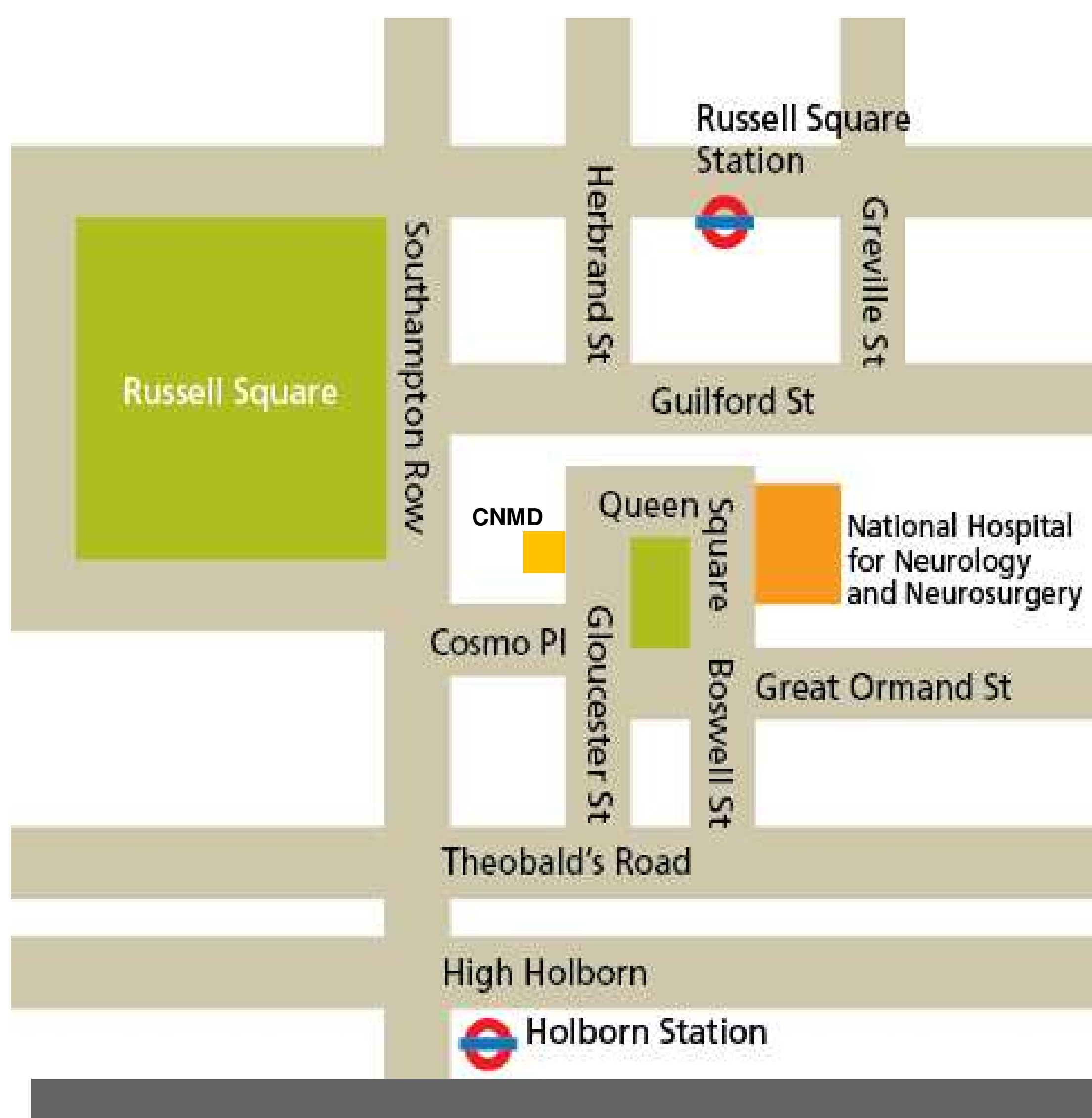
For further detail please also see the relevant Summaries of Product Characteristics (SPC) document at www.medicines.org.uk

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 outpatent 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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