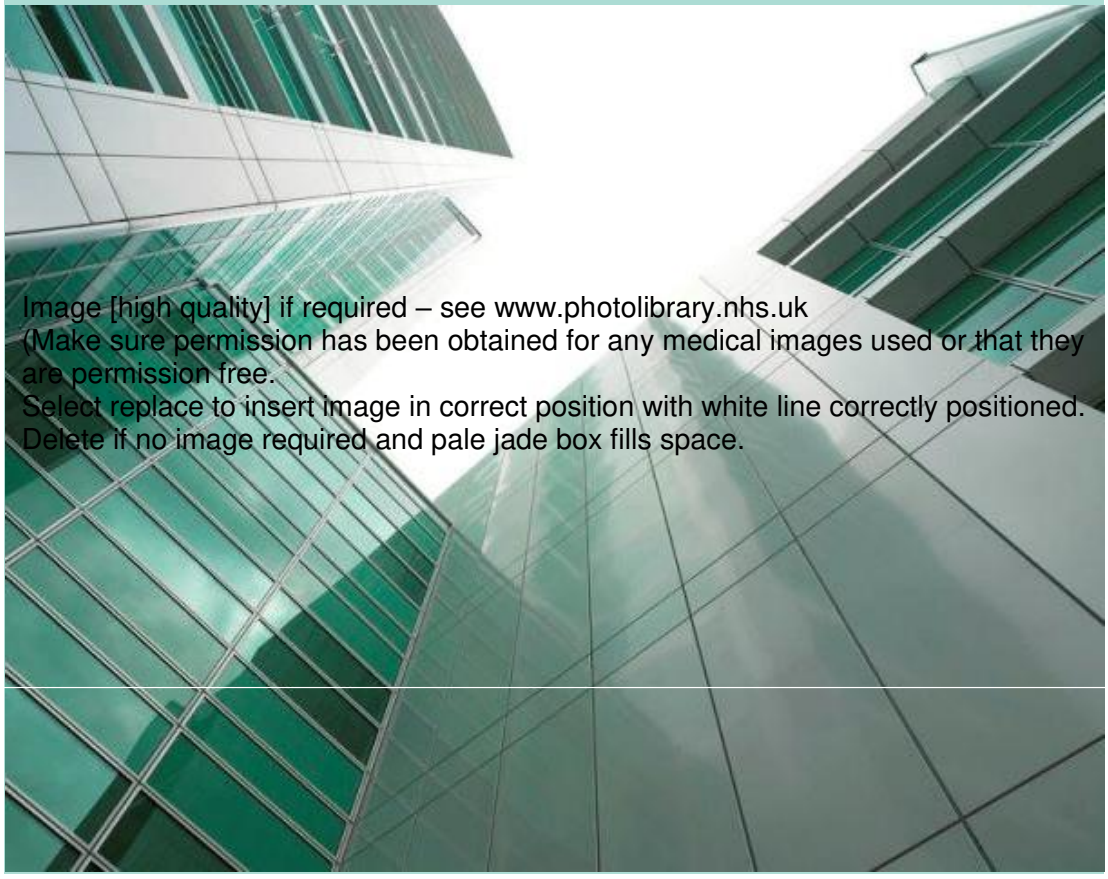
University College London Hospitals NHS
NHS Foundation Trust

National Hospital of Neurology and Neurosurgery

Queen Square Centre for Neuromuscular Diseases

Patient information leaflet:

Rituximab



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Introduction

This booklet discusses the use of rituximab 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 Rituximab?

Rituximab is a type of drug called a biological therapy. In some conditions, B-cells in the body produce harmful autoantibodies which attack the body's own tissues. Rituximab (trade name: MabThera) works by depleting the B-cells to reduce inflammation and improve your symptoms. If you respond well to rituximab, you'll probably feel better within 2–16 weeks.

Rituximab is used in the treatment of several inflammatory neuromuscular conditions including:

- Severe myasthenia gravis
- Polymyositis and dermatomyositis.
- Vasculitis
- It may be effective in other conditions but that hasn't been proven yet

Rituximab won't be started if:

- your disease isn't active
- you've not tried other treatments appropriate for your condition first
- you have an infection.

What are the possible side effects?

A few people experience a fever, wheeziness, a rash or fall in blood pressure during or shortly after the infusion, or you may feel unwell during infusions. If this happens, tell the person giving you the infusion so they can slow it down. If your symptoms are severe you may need to stop treatment, but this is rare.

Foster MA, *et al. Pract Neurol* 2023;0:1–14. doi: 10.1136/pn-2023-003708

What are the risks?

Rituximab affects your immune system, so you may be more likely to pick up infections. Tell your doctor or rheumatology nurse straight away if you develop a sore throat, fever or other signs of infection, or any other new symptoms that concern you.

You should also see your doctor if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. These illnesses can be more severe in people on rituximab, and you may need anti-viral treatment.

After three or four courses of rituximab, the levels of useful antibodies in your blood (the ones that protect you against infection) may go down. This may not be a major problem, but rarely it might mean that repeated courses increase your risk of infection. Your clinical team will discuss this with you before considering further treatment. Very rarely severe skin reactions have been reported with rituximab up to four months after the infusion. You should tell your doctor or rheumatology nurse straight away if you develop a rash after starting rituximab.

In very rare cases patients treated with rituximab have developed a serious condition called progressive multifocal leukoencephalopathy (PML), which can damage the brain and spinal cord. You must see your doctor immediately if you notice any of the following:

- pins and needles
- weakness, shaky movements or unsteadiness
- loss of vision
- speech problems
- changes in behaviour or mood
- difficulty with movements
- (face, arms or legs).

Reducing the risk of infection

Try to avoid close contact with people with severe active infections. For advice on avoiding infection from food, visit: www.nhs.uk/ Conditions/Food-poisoning/ Pages/Prevention.aspx

Having an operation

Planned operations are usually scheduled at least a month after your last infusion, so make sure your surgeon knows you’re on rituximab.

Is there any reason I won't be prescribed rituximab?

Your doctor may decide not to prescribe rituximab if you're pregnant or breastfeeding, or if:

- you have severe heart problems
- you get short of breath very easily
- your B-cell or antibody levels are low
- you have seronegative myasthenia gravis (with acetylcholine or MuSK antibodies).

Is there an alternative?

There are some alternatives to rituximab and they include medications such as cyclophosphamide, which has its own set of risks associated with 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?

Rituximab is given through a drip into a vein (intravenous infusion) in hospital. The first infusion takes around six hours, although following infusions will be a bit shorter.

The first time you get it, it will be given over 2 days two weeks apart, usually be attending our Day Care Unit (DCU). If your consultant decides that you need to continue on this drug you will receive further treatments over 1 day, six months apart.

You may have a steroid injection or infusion first together with paracetamol and an antihistamine to reduce the chance of a reaction.

How long does rituximab take to work?

If you respond well to rituximab, you'll probably feel better within 2–16 weeks.

Can I drink alcohol while taking rituximab?
You can drink alcohol while on rituximab but keep within the recommended limits for adults of no more than 14 units per week. Have alcohol free days, without 'saving up' units to drink in one go. If you're also taking methotrexate, you should try to keep well within these limits because methotrexate and alcohol can interact and damage your liver.

Should I get regular vaccinations?

If you're offered shingles vaccination (Zostavax) it's best if you can have this before starting rituximab. Otherwise, you may be able to have this between courses when your B-cells have returned, so check with your rheumatology team.

Pneumococcal vaccine (which gives protection against the most common cause of pneumonia) and yearly flu vaccines should be given at least one month before a course of rituximab.

Is rituxmab safe in pregnancy and breastfeeding?

Evidence suggests that rituximab is relatively safe in early pregnancy. Current guidelines therefore suggest you can continue rituximab treatment until you become pregnant. It can also be continued through your pregnancy if your underlying disease is severe and there are no safer alternatives. If you take rituximab in your third trimester, your baby should not have live vaccinations until they are six months old.

Guidelines state that men who are trying to father a child can take rituximab.

Rituximab is an antibody that can be passed on in breast milk. There is only limited information on its effect on your baby, but guidelines suggest it is safe to breastfeed while taking rituximab.

Foster MA, *et al. Pract Neurol* 2023;0:1–14. doi: 10.1136/pn-2023-003708

References

D Whittam et al., **Rituximab in neurological disease: principles, evidence and practice**. Practical Neurology 2019;19:5-20.

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Where can I get more information?

www.wikipedia.org/wiki/intravenous immunoglobulin
www.arthritisresearchuk.org

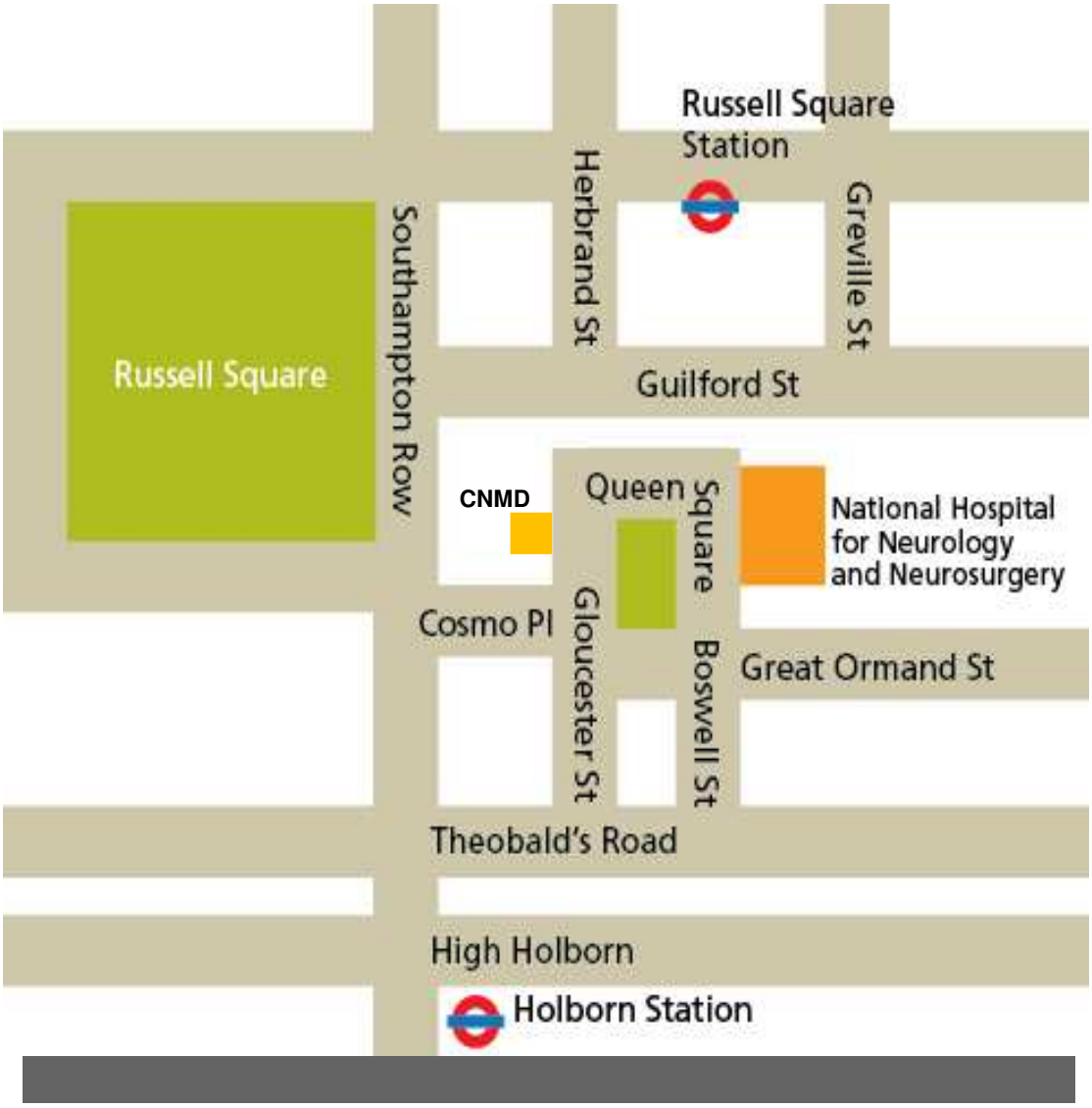
For further detail please also see the relevant Summaries of Product Characteristics (SPC) document at www.medicines.org.uk

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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