Rituximab to treat myasthenia gravis

This factsheet contains information about the use of rituximab to treat myasthenia gravis (a rare long-term condition that causes muscle weakness). It explains what rituximab is, what the treatment involves and the possible side effects. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to your consultant neurologist, specialist nurse or pharmacist.

What is rituximab?

Rituximab is a type of medicine known as a monoclonal antibody (man-made antibodies designed to bind to specific targets in the body and destroy them). It works by temporarily reducing the number of B-cells (a type of white blood cell that makes antibodies to help the body fight infection) in the body. In doing so, rituximab suppresses (dampens down) your overactive immune system response which is causing harm and leading to the symptoms of myasthenia gravis.

Rituximab has been approved and licenced in the UK for use in rheumatoid arthritis and for certain types of cancer. However, it has **not been formally approved** for use in any neurological conditions, and studies on its safety and efficacy (how effective it is) have only been done using a small number of people with these diseases.

Small studies have shown that when rituximab was given to people with an autoimmune condition, they experienced:

- a reduction in the number of attacks
- a reduction in symptoms
- an improved ability to carry out day-to-day activities

A more recent study (RINOMAX) has also shown that having rituximab early in the presentation of myasthenia gravis can help to significantly reduce:

- the number of hospital admissions
- the need to remain on high doses of corticosteroids for a long time

How is rituximab given?

Rituximab is given as an intravenous infusion (a drip) via a cannula (a small plastic tube) placed in a vein in your arm. It is given as a single dose. It will usually be administered in the neurology day unit by a specially trained nurse.

Is rituximab suitable for everyone?

Rituximab is **not** suitable for everyone. Please contact your consultant neurologist or specialist nurse for advice before starting the treatment if you:

- have previously had a hepatitis B infection. There is a risk that the hepatitis B infection may be reactivated by the treatment which can cause serious liver damage.
- have had or have heart problems. Occasionally, rituximab can worsen heart disease and cause irregular heartbeats. We will perform an electrocardiogram (ECG) (a test that records the electrical activity of your heart, including the rate and rhythm) either in clinic or on the day of your first infusion to check this before we begin the treatment.
- are or think you could be pregnant. The effect of rituximab on pregnancy and unborn babies is not known, so should be used with extreme caution in people who are pregnant. See section on pregnancy and breastfeeding later for more information.
- are currently breastfeeding. See section on pregnancy and breastfeeding later for more information.
- have had a very bad reaction to rituximab in the past.

How should I prepare for the treatment?

Eating and drinking

You can eat and drink as normal before the treatment.

Medications

If you take medication for high blood pressure, you should stop taking this for **at least 12 hours** before the treatment.

You can take all your other usual medications as normal before the treatment.

Items to bring with you

Infusions can take a few hours, so we recommend bringing in some form of entertainment, such as a book or an electronic device.

What will happen before the treatment?

Before your treatment, we will explain what the rituximab infusion involves, including the benefits and risks. This is a good opportunity for you to ask any questions that you may have. If you are happy to proceed with the treatment, we will then ask you to sign a consent form.

We will then perform an ECG (if we have not done so already) to check your heart before we begin the treatment.

As rituximab targets the immune system, it can sometimes cause:

- allergic reactions and anaphylaxis (a life-threatening allergic reaction that happens very quickly)
- flu-like symptoms

We will give you the following medications before you start having rituximab infusions to help prevent these reactions:

- a paracetamol
- a steroid
- an antihistamine (Piriton/chlorphenamine)
- an anti-sickness medication (if necessary)

Please let us know if you are unable to take any of these medications.

What will happen during the treatment?

We will give you the first infusion slowly over a few hours to reduce your risk of a reaction to rituximab. We will monitor you closely for any side effects during this time. If you do develop a reaction, we will stop the infusion, and a doctor will assess you and provide any necessary treatment. Once your symptoms have settled, we will decide whether it is appropriate for us to restart the treatment. You may need to stay in hospital overnight after the first treatment so that we can monitor you and make sure you are feeling well before you go home.

What will happen after the treatment?

You will be able to return to your usual daily activities immediately after your treatment as long as you are feeling well. Please note that Piriton can make some people feel sleepy, but this will usually wear off by the time the infusion has finished.

What are the possible side effects?

Immediate side effects

- Infusion related side effects (for example, flu-like symptoms, fever, chills, weakness, muscle aches, tiredness, dizziness or headaches)
- A drop in blood pressure
- Nausea (feeling sick) and vomiting
- An allergic reaction (for example, skin rashes, itching, a feeling of swelling in the tongue or throat, irritation of the nasal passages, wheezing or breathlessness)
- Severe skin reactions (for example, painful sores on your skin, in your mouth, ulcers, blisters or peeling of skin)

If you experience any of the side effects listed above, we will provide the necessary care and treatment while you are in hospital.

Late onset side effects (these may appear up to 6 to 12 months after the treatment)

- Breathlessness and fatigue (extreme tiredness) because of anaemia (a condition in which there are not enough red blood cells to deliver oxygen around the body or red blood cells that are unable to carry enough oxygen).
- A higher risk of infection. Contact your consultant neurologist or specialist nurse if:
  - your temperature goes above 38°C (100.5°F)
  - you feel unwell with a normal temperature (for example, if you have a sore throat, runny nose, cough or a burning pain when passing urine)
- Bruising or bleeding
- Progressive multifocal leukoencephalopathy (PML) – This is a very rare but potentially fatal side effect. It is a rare brain infection caused by the activation of a virus called ‘JC virus’. It can occur during or after treatment with rituximab. The symptoms of PML may be similar to the neurological symptoms you are being treated for. If you believe your symptoms are getting worse or if you notice any new symptoms, it is important that you speak to your consultant neurologist or specialist nurse **immediately**.

If you experience any of the side effects listed above, contact your consultant neurologist and specialist nurse for advice. You can also contact your general practitioner (GP) for additional advice.

How will I be monitored for side effects?

We will monitor you closely during the infusion. If you feel unwell or experience any of the immediate side effects listed in this factsheet during the infusion, let us know.

You will need to have a blood test two weeks after your first infusion to see whether your white blood cells (CD19 count) have fully reduced. This will help us to determine whether you need an additional infusion. If you do need another infusion, we will arrange for you to have this two weeks after your blood test.

At each clinic review, or at three-monthly intervals if you are on additional immunosuppression medication, you will need to have a blood test so we can check your full blood count and your kidney and liver function. This test will help us to monitor if your:

- white blood cell count drops too low
- platelet count drops too low
- number of red blood cells drops too low (you become anaemic)
- liver function is affected

How many infusions will I need?

One infusion contains one dose of rituximab. Depending on how effective the first infusion is (we will be able to determine this using a blood test), you may need to have a second infusion four weeks later. It can often take between 8 to 12 weeks for people to see the full benefit of rituximab. We may recommend you have an infusion every 6 to 12 months. If this is the case, we will discuss this with you.

Can I have rituximab if I am pregnant or breastfeeding?

Rituximab should only be used in pregnancy in exceptional circumstances where there is significant risk of harm from myasthenia gravis without treatment. This is because it is unknown what effect rituximab will have on an unborn baby.

While having rituximab infusions, it is very important that you use contraception (more than one method if possible) to prevent pregnancy. It is also unknown whether it is safe to try for a baby shortly after having rituximab. To reduce the potential risk, we recommend leaving a gap of 12 months after having your last rituximab infusion before **trying** to conceive.

Breastfeeding while having rituximab is generally considered to be safe as rituximab is a large protein. This means that the amount of rituximab that passes into your breast milk will be very low and any that gets to your child will usually then be destroyed by their digestive system, so they will only absorb a minimal amount. As long as your baby is not immunosuppressed (has a weaker immune system) for another reason, you should be fine to breastfeed your baby while receiving rituximab.

Can I take other medications at the same time as rituximab?

It is important that you tell your doctor what medications you are taking (including non-prescription and herbal therapies) before starting rituximab. This is because some medicines interact with rituximab, such as warfarin.

Vaccines

If you have myasthenia gravis and are being treated with rituximab, it is important that you **do not** have any **live vaccines**. This is because live vaccines can cause severe, or potentially fatal, infections in people who have a weakened immune system (immunosuppressed).

Although **non-live vaccines** are safe to have during rituximab treatment periods, rituximab will significantly reduce how well the vaccines work. For this reason, we strongly recommend that if you are due to have any **non-live vaccines** (for example, the yearly flu vaccine), you have these:

- **at least four weeks before** you start your first rituximab infusion or
- **at least four weeks after** you finish your last rituximab infusion.

Contact us

If you have any questions or concerns, please contact us.

Myasthenia gravis specialist nurse
Telephone: **023 8120 5948** (Monday, Tuesday, Wednesday and Friday, 8.30am to 3.30pm)

Useful links

www.nhs.uk/conditions/myasthenia-gravis

www.myaware.org

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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