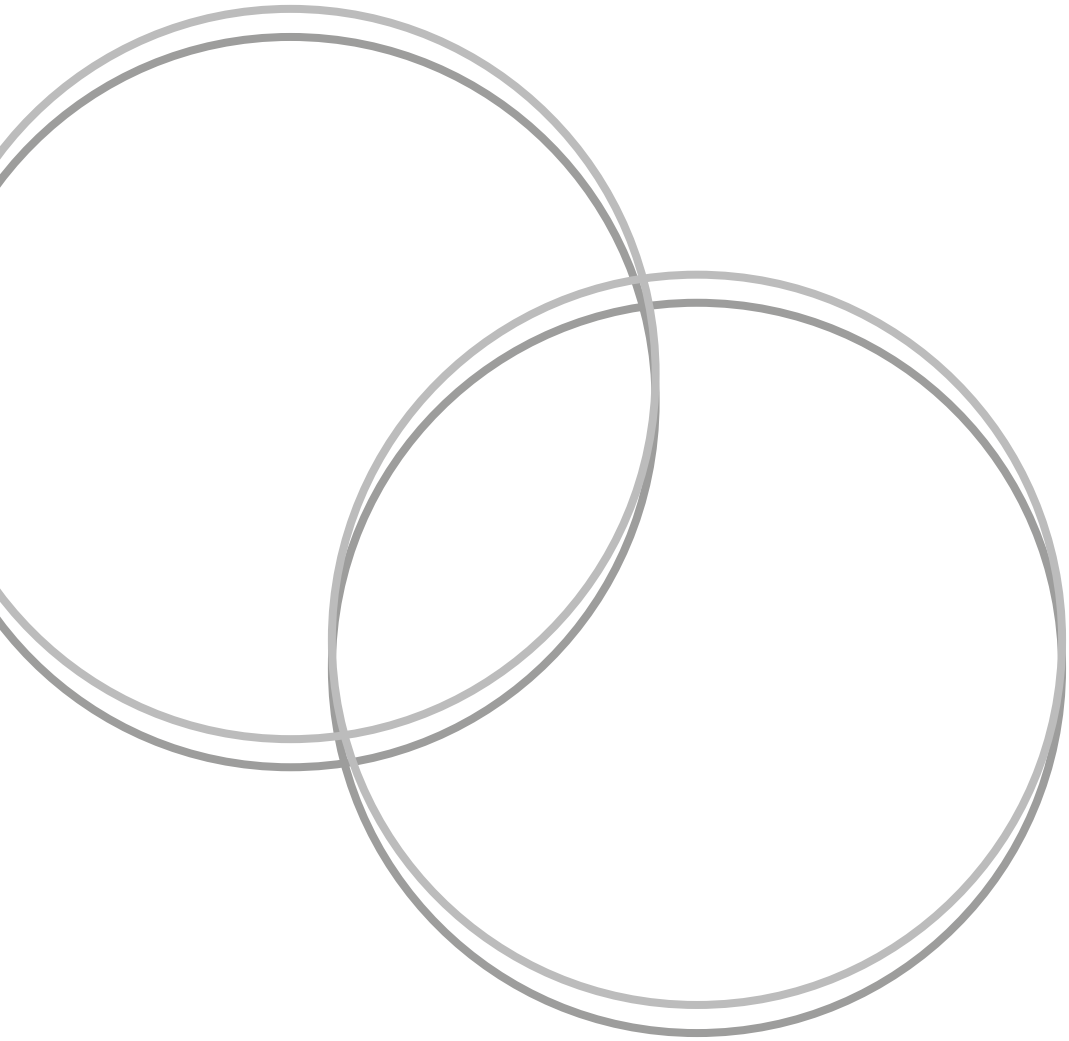
Oxford University Hospitals
NHS Foundation Trust

Rituximab:
Information for Patients with Autoimmune Blood Disorders

Information for patients



You have been diagnosed with an autoimmune disorder. This leaflet gives you information about rituximab, which is a treatment used to treat autoimmune disorders.

Why have I been prescribed rituximab?

You have been prescribed rituximab because you have either immune thrombocytopenia (ITP), thrombotic thrombocytopenic purpura (TTP), warm autoimmune haemolytic anaemia (wAIHA) or cold agglutinin disease (CAD). These are disorders in which your body's immune system attacks healthy parts of your blood.

Rituximab is licensed for the treatment of several autoimmune conditions including rheumatoid arthritis. It is not licensed for the treatment of ITP, TTP, wAIHA or CAD. This means that the drug company has not applied for a license to treat these conditions, although it is commonly used and recommended in national and international guidelines for the treatment of these disorders. Off-label use of rituximab for the treatment of ITP, TTP, wAIHA and CAD is supported by expert clinician groups. If you would like more information on unlicensed and off-label medicines, please speak to your doctor or nurse.

How does rituximab work?

Rituximab reduces the activity of your immune system. It is often used instead of steroids, which can have long term side effects such as bone thinning, weight gain, fluid retention (such as bloating in the face and swelling in the abdomen), and blood pressure changes.

Rituximab is a monoclonal antibody, which is a type of protein that sticks to the surface of a white blood cell called a B-cell. When rituximab sticks to the surface of a B-cell, the cell dies, therefore significantly reducing the number of antibodies attacking and destroying your healthy blood cells.

It can often take several weeks before it starts to take effect. If you respond well to rituximab, you will probably feel better within four to six weeks.

Rituximab is not made from donated human blood but is developed by a drug company.

How is Rituximab given?

Rituximab is given as an infusion through a cannula (a small tube inserted into a vein in your arm). It is administered once per week for four weeks (making a total of four doses). A maximum of eight doses may be given for some autoimmune disorders such as TTP. Rituximab can be given as an inpatient or outpatient procedure. It takes 2 to 4 hours for the full dose to be administered. The first dose is often given at a slow rate with close monitoring so that any side effects can be treated early.

If you receive rituximab as an outpatient, this will take place in the Haematology Day Treatment Unit or on the Haematology/Oncology Ambulatory Care Unit at the Churchill Hospital by specially trained nurses. You should prepare to be at the hospital for a half day when receiving your first dose. Subsequent doses may be quicker, depending on if any adverse reactions occurred following your first dose. Premedication will be given to prevent further adverse reactions if needed.

What are the advantages of rituximab?

Immune Thrombocytopenia (ITP)

For people diagnosed with ITP who continue to have a persistently low platelet count despite treatment with steroids, rituximab stops the immune system from destroying platelets. The platelet count will come back to normal (or near normal) for approximately 60 in 100 people treated with rituximab for ITP. Long term stable responses occur in 20 to 25 in 100 people. A repeat course of rituximab may be considered if the initial increase in platelet count response lasts at least 6 months after rituximab treatment has stopped.

Thrombotic Thrombocytopenia Purpura (TTP)

For people newly diagnosed with TTP, rituximab forms part of your treatment and then reduces the risk of TTP coming back. For people who have previously had TTP and whose ADAMTS13 activity level falls below normal levels, rituximab improves the ADAMTS13 activity in 95 in 100 cases. Your nurse or doctor will have discussed this with you at the point of diagnosis. If you have any questions, please speak to your nurse.

Warm autoimmune haemolytic anaemia (wAIHA)

For people diagnosed with wAIHA who continue to have a low haemoglobin (red blood cell) level despite treatment with steroids, rituximab stops the immune system from breaking down the red blood cells. In people with wAIHA, 75 out of 100 will have a good response to rituximab infusions, with the haemoglobin count increasing. If the haemoglobin drops after treatment has stopped, repeat rituximab treatment may be considered.

Cold agglutinin disease (CAD)

For people diagnosed with CAD who have low haemoglobin, rituximab stops the immune system from breaking down the red blood cells. In people with CAD, 50 out of 100 will respond to rituximab infusions, with the haemoglobin count increasing. Rituximab is usually only partly effective in CAD, with the haemoglobin levels improving but not returning to completely normal levels. If the haemoglobin drops after treatment has stopped, repeat rituximab treatment may be considered.

What are the risks of rituximab?

Most people who are treated with rituximab for an autoimmune disorder have no side effects. Possible side effects include the following:

Allergic reaction

An allergic reaction can occur while rituximab is being given or for up to two hours after treatment has stopped. Allergic reactions most commonly occur during the first infusion. You will be given medication before the infusion to reduce the chance of an allergic reaction.

Allergic reactions are often mild. If you have an allergic reaction, the nurse administering treatment can usually manage this by slowing or stopping the infusion. You may require additional treatment such as an antihistamine or paracetamol. When the symptoms improve, the remainder of your rituximab infusion will be given at a slower rate to minimise the risk of any further reaction. These reactions are less likely to happen after the second infusion.

If your reaction is deemed severe, the rituximab will be stopped, and your doctor will be informed.

The nurse will check you for signs of an allergic reaction, but always tell your nurse or doctor **immediately** if you have any of the following symptoms.

- Breathlessness, wheezing or a cough.
- A rash or feeling itchy.
- Feeling unwell or sick.
- Flu-like symptoms such as headaches, feeling flushed, fever, chills, shivering or dizziness.
- Pain in your back, stomach or chest.

Rarely, people may have a reaction a few hours after the treatment has stopped. If you develop any of the above symptoms, or feel unwell after you get home, contact the hospital for advice. Contact details are provided towards the end of this leaflet.

Risk of infection

Rituximab doesn't increase the risk of developing an infection, but people can become more unwell if they get an infection after taking rituximab. If you develop any signs of an infection such as a fever, cough, sore throat, feeling weak or being generally unwell, tell your nurse or doctor. Before receiving rituximab, you will be screened for viral infections including Hepatitis B, as rituximab can reactivate viral infections or make them more serious.

Changes in blood pressure

For some people, blood pressure can become lowered whilst they are having a rituximab infusion. If you usually take medicine to lower your blood pressure, let your nurse or doctor know prior to starting the infusion. Rarely, rituximab can make your blood pressure increase. Your nurse will check your blood pressure regularly during your infusion to monitor any changes.

Raised blood sugar levels

Rituximab may raise your blood sugar levels. Symptoms of a raised blood sugar include feeling thirsty, needing to pass urine more often than normal or feeling tired. Tell your nurse or doctor if you have these symptoms.

If you have diabetes, you may notice your blood sugar levels may be higher than usual. Your nurse or doctor will talk to you about how to manage high blood sugar levels.

Skin changes

Rituximab may cause an itchy rash. You may also notice unusual feelings in your skin, such as numbness, tingling, pricking, or burning. Rarely, skin reactions can be more severe such as skin blistering. Tell your nurse or doctor if you notice any skin changes. Your doctor can give you advice and may prescribe medicines or creams to help. Any changes to your skin are usually temporary and will improve when your course of rituximab is complete.

Muscle and/or joint pain

You may get pain in your joints or muscles while having rituximab treatment. Tell your nurse or doctor if the pain does not get better after treatment has stopped. If you experience joint or muscle pain, a doctor may prescribe painkillers to help.

Effects on your nervous system

Rituximab can affect your nervous system. You may feel anxious, restless, dizzy, or have trouble sleeping. Tell your nurse or doctor if you notice any of these symptoms. It is important not to drive or operate machinery if you notice these effects.

Effects on your lungs

Rituximab can cause changes to your lungs. If you notice wheezing, a cough, or feel breathless, always tell your nurse or doctor. You should also let them know if any existing breathing problems get worse. Your doctor may arrange for you to have tests to check your lungs.

Diarrhoea and constipation

You may have diarrhoea, constipation, or stomach pain while taking rituximab. Your doctor can prescribe medication to help with these issues. Make sure you keep well hydrated and drink at least two litres of fluid every day if you have diarrhoea or constipation.

Less common side effects of rituximab

There are also less common side effects with rituximab, which include the following:

Hepatitis B reactivation

If you have had Hepatitis B (a liver infection) in the past, rituximab can make it active again. Your nurse or doctor will talk to you about this and take a blood sample to test you for Hepatitis B before prescribing rituximab. If you have active Hepatitis B, you cannot be treated with rituximab, as it can make your infection more serious.

Hearing problems

Rarely, rituximab may affect your hearing. Tell your nurse or doctor if you notice ringing in your ears (tinnitus), if you have other hearing changes, or if you experience pain in your ear after you start rituximab. These changes will improve when you complete your treatment.

Changes in the way your heart works

If you have any chest pains, difficulty breathing or swollen ankles, seek urgent medical attention. If you already have heart problems (such as angina, palpitations, or heart failure), rituximab may make them worse.

What should I do if I have any side effects?

If you experience any side effects during the infusion, immediately tell your nurse or doctor. If you experience any side effects after you have left the hospital, contact the Haematology Triage team on: **01865 572 192**.

Contact Haematology Triage if you develop unexplained bruising, bleeding, shortness of breath, excessive tiredness, yellowing of the skin or the whites of your eyes, or severe itching. This can be a sign of liver damage.

If you come into close contact with anyone who has chickenpox or shingles, tell your doctor as soon as possible.

Starting new medications

Before you start any new medications, including over the counter medications or herbal remedies, you must check with your doctor or pharmacist to ensure that they do not interact with rituximab.

There is no need to avoid alcohol during rituximab treatment, although drinking in moderation is advised.

Vaccinations

Tell your doctor prior to starting treatment if you think you may need any vaccinations including flu, pneumonia or COVID. This includes vaccinations needed to travel to other countries.

You should avoid having live vaccinations during treatment with rituximab and for at least six months afterwards. Live vaccines include BCG (tuberculosis), yellow fever, measles, mumps, rubella (including combined MMR), poliomyelitis, and liquid typhoid.

Rituximab does not appear to increase the risk of contracting a viral infection, but the illness can be more severe if you catch it whilst the effects of this treatment are still in your system.

Pregnancy and contraception

You must tell your nurse or doctor if you are pregnant, think that you might be pregnant, or are planning to become pregnant. This is because rituximab can cross the placenta and may affect your baby.

It is advised that you do not become pregnant, or father a child, during treatment with rituximab, as it may harm a developing baby. It is therefore important to use effective contraception during treatment with rituximab and for 12 months after treatment has stopped. If you have any questions, discuss them with your nurse or doctor prior to starting treatment.

Breastfeeding whilst taking rituximab

There is a risk that rituximab may enter breast milk in very small amounts. As the long-term effects of rituximab on breastfed infants is not known, as a precaution, breastfeeding is not recommended during treatment with rituximab and for at least six months after the treatment has stopped.

Driving and using machines

It is not known if rituximab affects your ability to drive or use any tools or heavy machinery. You may be given medication for a potential allergic reaction, such as an antihistamine, which may cause drowsiness. If so, you should avoid driving, cycling, or using any tools or heavy machinery while these effects last. Speak to your doctor or nurse if you have any questions or concerns.

Consent

We will ask you to sign a consent form prior to starting rituximab treatment. This will happen following a discussion about rituximab treatment with your doctor, during which the benefits, risks and potential side effects will be explained to you. You will also be given a chance to read the patient information leaflet prior to signing the consent form. The consent process will be completed during your outpatient clinic appointment or on the Haematology Day Treatment unit prior to starting your treatment.

How to contact us

Please discuss any areas of concern with your nurse or doctor in clinic.

For questions about your appointment, please contact:

Haematology Day Treatment Unit Administration Team
Telephone: 01865 235 554

If you feel unwell after your treatment, please contact:

Haematology Triage Team
Telephone: 01865 572 192

This is a 24 hour telephone help line (including after 5pm, weekends and bank holidays). You will speak to an experienced nurse who can discuss your symptoms with a doctor. You may be asked to attend the Haematology Triage Unit at the Churchill Hospital to be seen by a doctor.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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