Rituximab in Acquired Haemophilia A

This leaflet aims to answer your questions about having rituximab to treat your Acquired Haemophilia. If you have any questions or concerns, please speak to a doctor or nurse caring for you.

What is rituximab?
Rituximab is classed as a monoclonal antibody that is sometimes used in treating patients with cancer. It can also be very useful in managing patients with Acquired Haemophilia A. In Acquired Haemophilia A your immune system has been triggered to neutralise the factor VIII (eight) that your body makes naturally. This causes you to have bruising and other bleeding symptoms as your body is no longer able to stop bleeding as it normally would. Rituximab works by depleting the cells in your body that are neutralising your clotting factors so your factor VIII can work as it should.

How do I take the medicine?
Rituximab is an infusion that is given through your veins. In patients with Acquired Haemophilia A we give rituximab once a week for four weeks. If you have a PICC line it can be given through that, otherwise your nurse will insert a small plastic tube called a cannula into your vein. You will be given some paracetamol and chlorphenamine, an antihistamine, 30-60 minutes before the infusion starts.

Your first dose of rituximab is given very slowly over approximately six hours. If you tolerate this well it can be administered slightly more quickly the next time you have it.

What should I do if I miss or can’t make an appointment for rituximab?
Please contact the Haematology Day Unit as soon as possible so that they can reschedule you. This is to avoid your dose of rituximab going to waste.

Are there any side effects?
Some patients have an allergic reaction to rituximab, this is usually during the first or second infusion but it can happen during any of the infusions. This is why the first dose is given so slowly and why you will be given an antihistamine before each dose. Symptoms of an allergic reaction include can include a tingling sensation in your throat, feeling hot, shivering, headache, itchiness, wheezing, breathlessness, rash, pain in your back, stomach or chest, swelling in your mouth or throat or feeling
generally unwell. It is important that if you develop any of these symptoms you immediately tell the nurse looking after you. Sometimes a reaction can happen a few hours after treatment. If you develop any symptoms or feel unwell after you get home, contact the hospital straightaway.

Rituximab may also cause reactivation of Hepatitis B, if you have previously had a Hepatitis B infection. You will be tested for Hepatitis B before you start rituximab and if necessary we may give you extra treatment for this.

Rituximab affects your immune system and you may be more likely to pick up infections. Contact the hospital immediately if you have a temperature above 37.5 degrees Celsius, any other signs of an infection or if you feel generally unwell. Avoid people who are unwell and follow NHS guidelines on avoiding food poisoning.

Please also inform us if you are exposed to anyone with chicken pox or shingles as we may need to give you extra treatment to protect you.

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
- unsteadiness
- loss of vision
- speech problems
- changes in behaviour or mood
- difficulty with movements.

Is there anything else I need to know?

**Pregnancy/breastfeeding:**
Current guidelines advise women to avoid becoming pregnant up to six months after treatment with rituximab. Please ensure you are using appropriate contraception for this timeframe. It is safe for men who are using rituximab to father a child. The antibody in rituximab can be passed on in breast milk. Therefore do not breastfeed whilst you are receiving this medication.
**Vaccinations:**
Please discuss any vaccinations with the haemophilia team prior to receiving them. It is generally recommended that people receiving rituximab avoid live vaccines such as yellow fever.

**Herbal remedies and over the counter medication:**
Please do not take herbal remedies or new medication without first discussing it with the haemophilia service.

Please ensure you have someone to take you home from hospital after your first two treatments of rituximab.

**Useful sources of information**
https://rarediseases.org/rare-diseases/acquired-hemophilia/
https://www.nhs.uk/live-well/eat-well/10-ways-to-prevent-food-poisoning/

This leaflet was produced based on information obtained from Macmillan and Arthritis Research UK.

**Contact us**
If you have any questions or concerns about rituximab, please contact the haemophilia office on 020 8725 0763 (Monday to Friday, 8am to 5pm). Out of hours, please contact the haematology registrar via the hospital switchboard.
If your query is in regards to your appointment for rituximab please call the Haematology Day Unit on 020 8725 1680.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

**Additional services**

**Patient Advice and Liaison Service (PALS)**
PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).
Tel: 020 8725 2453  Email: pals@stgeorges.nhs.uk

**NHS Choices**
NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** www.nhs.uk
NHS 111
You can call 111 when you need medical help fast but it’s not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. Tel: 111

AccessAble
You can download accessibility guides for all of our services by searching ‘St George’s Hospital’ on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

Reference: HAE_RAHA_01  Published: September 2020  Review date: September 2022