

Patient information

Rituximab

Rheumatology and Nephrology Specialties

Rituximab is used in the treatment of a range of autoimmune diseases in the Rheumatology and Nephrology Specialties.

Autoimmune disease happens when the body's natural defence system cannot tell the difference between your own cells and foreign cells. The immune system creates autoantibodies against the body's tissues which in turn causes inflammation and damage.

Most autoimmune diseases cause inflammation that can affect many parts of the body. The parts of the body affected depend on which autoimmune disease a person has.

Your Consultant / Doctor has advised you to have rituximab for the treatment of your autoimmune disease.

What is rituximab?

Rituximab is a biological drug known as a monoclonal antibody. It works by removing a type of blood cell called a "B cell" which is involved in the making of autoantibodies. It is widely used for a variety of autoimmune diseases but only licenced for rheumatoid arthritis.

What are the benefits of having rituximab?

As mentioned above, there is abnormal activity of the immune system including "B cells" and by removing these cells with rituximab can control the condition by preventing disease progression and reduce damage.

What are the risks of having rituximab?

A small proportion of people within the first two hours of the infusion develop fever, wheeziness, rash, fall in blood pressure, chills and shivering. Pre-medication with paracetamol, steroid and an antihistamine given before the infusion significantly reduces the incidence of these infusion related reactions. If you develop any symptoms during the infusion, you should tell the person giving the infusion straight away, because it may be necessary to slow down the rate of the infusion.

Other less common side effects experienced during infusion are itching of your skin, sickness, tiredness, headache, breathing difficulties, sensation of the tongue or throat swelling, itchy runny nose, flushing, back pain and irregular heart rate.

Rituximab may rarely also cause abnormalities of your blood and affect liver function.

There is an increased risk of infections after rituximab, but this is unusual in practice. However, if infections do develop, they may be more severe.

Other undesirable effects have been recorded after administration of rituximab. Most are mild, but some are more serious complications, which fortunately are rare.

The adverse effects recorded include rashes, difficulty in sleeping, pain in muscles and joints, pain at the infusion site, anxiety, dizziness, tingling or numbness in hands or feet, sweating, abnormal taste, cough, reactivation of viral infection (e.g., cold sores), heart problems.

Additional information

Despite the list of side-effects, over a million patients worldwide have received rituximab and serious side-effects have been rare. For the great majority of patients, rituximab is a valuable treatment option and well tolerated.

In very, very rare cases patients who have been treated with rituximab have developed a disease of the brain and spinal cord called progressive multifocal leukoencephalopathy (PML). This is caused by a virus. If you experience memory loss, trouble thinking, difficulty walking and / or loss of vision please contact your doctor or nurse immediately.

If you developed PML the rituximab infusions together with any other immunosuppression would be stopped immediately and you would also be assessed by a specialist in infectious diseases for further management.

Tell your doctor about any medicines you are taking, including over-the-counter drugs. Rituximab can interfere with the blood thinning drug warfarin. Complimentary therapies and herbal drugs can be harmful to you when you are having Rituximab.

Recommendations for rituximab in pregnancy and breastfeeding

Pregnancy

There is currently no evidence that rituximab used by the father can harm the baby through effects on the sperm.

For women, it is always better to plan pregnancy with your medical team to ensure that you are well controlled with respect to your disease and that all medications are checked for safety in pregnancy.

You will usually be advised to stop rituximab six months before trying to have a baby. However, sometimes rituximab is continued right up to conception and there are occasions where rituximab is started or continued in pregnancy, where the possible benefits outweigh the potential risk.

If this is thought to be the case, a careful and thorough discussion with you and the wider multi-disciplinary team will happen before treatment to ensure all agree. A more detailed patient information leaflet on this topic is available, please ask if you would like a copy.

Your team will talk to you if that is the case for you and usually you will have counselling in the combined pregnancy clinic, if the situation is not an emergency.

Tell your medical team if you become pregnant whilst taking rituximab. If you accidentally take rituximab early in your first trimester, it's unlikely to be harmful.

If a mother does have rituximab during the last third of pregnancy, it is important that the baby has **no live vaccinations** until they reach six months of age. This usually means not having the rotavirus vaccine, which is given by mouth to your baby at eight weeks and twelve weeks of age. Occasionally it also means delaying a tuberculosis (TB) vaccine if that is offered (it isn't given to all babies). All of the other childhood vaccines are ok and can be given. If you are not sure, then check with the person giving the vaccine or your rheumatology team.

Breast- feeding

Limited data suggest that the amount of rituximab in breast milk is very low, it is likely to be partially destroyed in the infant's gut and absorption by the infant is probably minimal. The manufacturer recommends that breast- feeding be discontinued during rituximab therapy and for 12 months following rituximab treatment. However, some organisations including British Society of Rheumatology have produced guidelines indicating that breastfeeding can be considered during treatment. Please ask for further detailed information should you require it.

Vaccinations

If immunisations are needed, they should be given at least two weeks before rituximab. Live vaccines should be avoided.

You can drink alcohol whilst on rituximab but keep within the recommended limits.

If you are worried about any of these risks, please speak to your consultant or a member of their team.

What will happen if I decide not to have treatment?

Your disease will not be controlled. Where there are contraindications, alternative treatment modes will be discussed.

Getting ready for your rituximab infusion.

Rituximab is given by injection (intravenously) through a fine tube (cannula) inserted into a vein.

It is initially given as a two-dose course of treatment with a two-week interval between doses known as induction treatment.

Some patients will require further maintenance treatment six months after induction treatment. Maintenance treatment is a one-dose course given at six monthly intervals for a selected period of time.

Rituximab treatment will be given in a ward or day case unit and the infusion takes approximately six hours. Your future appointment will be clearly explained to you.

You will be given medicines to prevent or reduce fever or allergy at each infusion.

During the infusion the nurses looking after you will be monitoring you closely.

The response to rituximab is often evident after about six weeks.

Please leave all cash and valuables at home. The Trust does not accept responsibility for items not handed in for safekeeping.

Going Home

After the infusion is completed, the cannula will be removed and you will be able to go home. We do not advise that you drive home after the infusion.

Discharge Information

You may have a reduced resistance to infection.

You may be given long term Prophylactic Antibiotics to prevent Pneumocystis Pneumonia (PCP).

The nursing staff will advise you about your specific medication.

You may require blood testing in-between induction treatment doses.

If you become unwell or develop:

- a temperature above 38 'C
- coldness or shivering
- any unexplained bruising or bleeding
- severe diarrhoea
- unrelieved shortness of breath
- mouth ulcers that stop you eating or drinking.

Please contact your specialist nurse team:

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Rheumatology Nurse Team: Monday – Friday

If your treatment is at Broadgreen Hospital (Rheumatology):-

Vasculitis Helpline

Tel: 0151 282 6052

Lupus Helpline

Tel: 0151 282 6047

Rheumatology Nurse Helpline

Tel: 0151 282 6060

Broadgreen Hospital Ward 4

Tel: 0151 282 6758

If your treatment is at Aintree Hospital (Rheumatology):-

Vasculitis/ Behcet's Helpline

Tel: 0151 529 8123

Rheumatology Nurse Helpline

Tel: 0151 529 3034

Lupus Helpline

Tel: 0151 282 6047

Aintree Hospital Medical Day Case Unit

Tel: 0151 529 8076

Nephrology Immunosuppression Nurse and Pharmacist Team:

Monday - Friday

Immunosuppression (Vasculitis and Lupus Nephritis) Nurse Team Royal Liverpool and Aintree Hospital (Nephrology):-

Tel: 0151 706 3188

Royal Liverpool Hospital Secretaries (Nephrology):-

Tel: 0151 706 3429

Aintree Hospital Secretaries (Nephrology):-

Tel: 0151 529 8797

Broadgreen Hospital Ward 10

Tel: 0151 706 2396

Aintree Hospital Medical Day Case Unit

Tel: 0151 529 8076

Out of Hours

NHS 111

Tel: 111

Useful Websites

www.vasculitis-uk.org.uk

www.lupusuk.org.uk

www.myositis.org.uk

www.nras.org.uk

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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