

Rheumatology

Welcome to the Biologics Service

You and your consultant have decided that the next stage of treatment for you is a biologic drug. Your joint count, disease activity score (DAS) or Bath Disease activity index (BASDAI) has confirmed that your disease is active and that you meet initial criteria for the medication. You will also have a CXR and blood tests.

What happens next?

Now you have made the decision to start biologic treatment you will be referred to the biologics service to arrange education and complete your screening

The education will either be in a group or on a one-to-one basis.

The treatment options will be discussed and you will be provided with written information.

There is a screening questionnaire to be completed and any outstanding investigations will be requested.

The medication options are either by injection's given by you under the skin (subcutaneous) or by infusion in hospital

Once you have decided that you want the medication we ask that you give verbal consent.

We also ask that you consent to the home delivery company having your details for checking the prescription is correct and for delivery purposes

In some cases we may need to contact your Clinical Commissioning Group (CCG) to request funding for the medication. This part of the process may take some time



Nurse Specialists

We are here to offer patients and their families support and advice as part of the biologics team. We will listen to your concerns and talk about the treatment plan.

We are also accessible between appointments if you have any queries or concerns. Please see the contact details on the back page.

What do you need to do after you start the medication?

- You will need to make sure that you or your representative is available at the planned delivery time
- **Regular blood tests are essential to ensure that you are safe while on your treatment. These will be monthly for the first six months and then drop to three monthly if there are no concerns. Frequency may change over time or in response to circumstances**
- If you have not heard from the home care company about your next delivery **check if your blood tests are up to date.**
- Tell the homecare company if you get down to less than two weeks supply of medication so that there is enough time to arrange your delivery before you run out.
- Inform the biologics office if your address or contact details change
- Store your medication correctly
- If you need to change any aspect of the delivery then please contact the homecare company as far in advance as possible to ensure that you get a suitable delivery slot.
- If you are unable to do any of this it may not be possible to supply your medicines using the home delivery service
- We ask that you let us know after you have had your first dose. You will be sent an appointment to see the specialist nurse three – four months later.
- At that visit the effectiveness of the medication will be assessed using the same assessment tools as before. You will be reassessed again at six months



- At that visit the effectiveness of the medication will be assessed using the same assessment tools as before. You will be reassessed again at six months
- If you have responded positively and your disease remains well controlled you will continue on treatment and have six monthly appointments.
- These assessments are very important and essential for continuation of treatment. They should be completed accurately and on time. This will demonstrate to the CCG that you are responding to treatment to ensure continuation of funding.

Your treatment could be withdrawn if you do not attend your appointments.

IF YOU NO LONGER REQUIRE YOUR MEDICATION PLEASE CONTACT YOUR SPECIALIST NURSE IMMEDIATELY

Frequently asked questions

1. **What should I do if I experience side effects from my new treatment?**

If the side effects are mild stop until the side effect settles then retry the drug

If the side effects are serious stop and contact us

2. **Which vaccinations are safe for me to have with my medications?** We recommend that you have the pneumococcus vaccination (a one off vaccine) and a yearly flu vaccination. If you are on Rituximab your flu vaccination must be 4-6 weeks before your next infusion or at least 6 months after.

For a few diseases, the vaccine is in the form of a live virus. People on biologics therapy should not have live vaccinations

Examples of live vaccines are: Yellow fever and shingles.

If you are unsure whether or not to have a vaccination check with your travel nurse or rheumatology nurse first.

3. **Should I stop my DMARD/biologic if I am unwell?** If you feel unwell or are on antibiotics we advise you to delay your medication. Wait until you feel better and/or the antibiotics have finished and you are infection free.

4. **Bloods monitoring on biologics/DMARDs.** Regular blood tests are essential to ensure that you are safe while on your treatment. These will be monthly for the first six months and then drop to three monthly. Frequency may change if there are changes to your medication or if you have abnormal blood results



5. **What are the common side effects of DMARDs/biologics** – these are listed on the drug information sheet you were given

6. **What do I do if I come into contact with someone who has chicken pox/shingles or get chickenpox/shingles?**

If you come in contact with someone who has chickenpox/shingles:

Stop your biologic (as well as any other DMARDs) until you have spoken to the nurse specialist on 01225 473408 or 01225 428823.

Out of hours speak to your on call GP who can liaise with our medical team.

7. **What do I do if I get chickenpox/shingles?** If you develop chickenpox/shingles

Stop your biologic (as well as any other DMARDs) until you have spoken to the nurse specialist on 01225 473408 or 01225 428823.

Out of hours speak to your on call GP who can liaise with our medical team.

If emergency you may need to attend A&E

8. **What do I do if my disease flares?** It is possible to self-manage flares with a few days of rest, taking prescribed painkillers i.e. Paracetamol and anti-inflammatory medications i.e. ibuprofen. In some cases where the symptoms do not improve you may need to see a health care professional. This may be your GP or one of your rheumatology team to discuss treatment options. This can include short-term management with steroids or if your flares are persistent or occur on a regular basis you may need your treatment plan revisiting.

If you have a flare of a single joint an injection of the joint may help

Sometimes it can help to apply an ice pack, a heat pack, or a wheat pack (you can buy these at your local chemist) to an individual joint that is causing pain.

If you find an ice pack helps, be careful not to burn yourself, use a cloth to protect the skin.

If this does not work it is advisable to contact a member of the rheumatology team for advice - see back page for telephone numbers



9. When is my next appointment? – if you are unsure when your next appointment is **please ring appointments on 01225 473401** (answer machine most days) and leave a message - they will ring you back. Or email ruh-tr.RNHRDOutpatientAppointments@nhs.net

10. What should I do if I am having surgery?

There are no formal guidelines regarding when to stop biologic/Anti-TNF treatment in readiness for surgery but our advice is you should let your surgeon know you are on a biologic therapy.

For most surgery patients should stop their biologic therapy 2 week prior to surgery unless you are having Rituximab: in which case we advise surgery is planned for at least 4 weeks after the last infusion.

Please call the advice line if you are unsure or need further advice.

Re-commencement of treatment can only start when the wound is healed and there are no signs of infection.

11. What should I do to avoid infections? For advice on avoiding infections from food visit the NHS choices- food poisoning prevention webpage

www.nhs.uk/conditions/food-poisoning/prevention

Try to avoid close contact with people with severe active infections

Websites for advice/support

- Versus Arthritis homepage
www.versusarthritis.org
- NASS homepage
www.nass.co.uk
- National Rheumatoid Arthritis Society
www.nras.org.uk



Helpline Numbers

- Versus Arthritis Helpline
Tel: 0800 5200 520 (open Mon-Fri, 9am – 8pm)
www.versusarthritis.org
- NASS Helpline
Tel: 020 8741 1515 (open Mon – Fri, 9am – midday)
www.nass.co.uk/contact-us
- National Rheumatoid Arthritis Society
Tel: 0800 298 7650 (open Mon – Fri 09.30am – 4.30pm)
www.nras.org.uk/helpline
- Vasculitis UK
www.vasculitis.org.uk/helpline
- SRUK, for scleroderma patients
www.sruk.co.uk/find-support/helpline

Further information can be obtained from:

Royal National Hospital for Rheumatic Diseases

RNHRD & Brownsword Therapies Centre

Combe Park

Bath

BA1 3NG

Rheumatology Support line 01225 428823

Answer machine open Mon-Fri 0900-1200

Biologics Office

01225 473408 (no answer machine)