

Further sources of information

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them.

If you require a full list of references (if relevant) for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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INFORMATION FOR PATIENTS

Rheumatology Department

Biologic Therapy Initiation

Email: sfh-tr.rheumqueries@nhs.net

Rheumatology helpline number: 01623 676002

Website:

<https://www.sfh-tr.nhs.uk/our-services/rheumatology/>

This advice supplements information provided by Arthritis Research UK and rheumatology counselling sessions.

Please read and keep this leaflet and ask the rheumatology team if you have any questions.

What are biologics?

Medication which block specific chemicals made within your immune system. These help reduce inflammation, stiffness and damage to joints, but they are **not** painkillers. They have successfully been used for many years and are carefully chosen to suit you.

What are biosimilars?

Newer similar versions of the original biologic medicine. These can be compared to leaves on a tree. They appear the same and serve the same purpose, but under the microscope there will be a very small degree of difference.

Switching patients to a biosimilar medicine can save the NHS hundreds of millions of pounds. However, biosimilars are **not** 'cheap copies'. They are thoroughly tested in clinical trials to show they work just as well and are just as safe as the original biological medicine, so you shouldn't notice any difference at all.

Because there are different types of biologics, it is important you know which **brand** you have been prescribed.

How long do they take to work?

You may notice a difference in the first couple of weeks, but it often takes up to three months. So, it is important you keep using it, even if it doesn't seem to be working at first.

Taking medication weekly, fortnightly or monthly can be difficult to remember. Write it in your diary and/or set an alarm or reminder on your phone/computer. Sticky labels on calendars and phone apps are also available.

Name of patient:

My biologic:

Checklist for what happens next:

- You will have a blood test and chest x-ray.
- Receive your vaccines from your GP four weeks before treatment:
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If receiving self-injecting medication or tablets:

- We will arrange your prescription and will send to Homecare. In four weeks, they'll contact you to arrange a convenient delivery time.
- A Homecare nurse will then contact you to provide teaching.
- Phone or email the rheumatology advice line (see the front page) to inform us of the first day you have administered the medication.
- At six weeks, you will receive a telephone call from us to see how you are getting on.
- Two weeks before running out of medicine, please contact Homecare. We will arrange further prescriptions and Homecare will deliver (usually every eight to twelve weeks).

If receiving a drip:

- A pre-infusion clinic appointment will be arranged.

Notes:

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How will I receive my medication?

If self-injecting or taking tablets: Medication is dispensed via a private Homecare delivery service.

If self-injecting: A nurse from the Homecare company will teach you how to inject. They usually visit twice but can come more often if necessary. They will also provide a yellow sharps bin to dispose of your medication safely. Do not throw your device in household waste, as they can injure other people.

Please note these medicines are extremely expensive. If you **DO NOT** require any more medicine, tell Homecare when they contact you. If they try to deliver it, do not accept the delivery. Otherwise, we have no choice but to pay for it and throw the medicine away. More information can be found on the additional homecare leaflet.

Infusions/drips: If you are receiving your biologic via a drip, you will receive a couple of extra appointments. These are for a pre-infusion clinic and the dates of your actual drip. You **MUST** attend all appointments. Infusions are administered at the Welcome Treatment Centre at King's Mill Hospital.

Research

You may get asked to take part in a research study about biologic drugs. We continue to carry out research on these therapies even though many have been on the market for a long time. This research helps us understand even more about why people with similar conditions may respond differently to the same medicine.

Carry your alert card

Carry your alert card at all times. Show this to all other healthcare professionals (dentist, pharmacist, surgeon, other consultants), especially if starting new medication, you are admitted to hospital or you are feeling unwell. They may not necessarily know what you are taking, as it will not appear on your repeat green prescription.

What common side effects can I expect?

For most people they are well tolerated, but these **could** happen:

- **If self-injecting:** The area of skin around the injection site becomes red, swollen or painful. This disappears over time and is prevented with good injection technique. Antihistamines or cream can be purchased from your pharmacy. If severe, please see below 'When do I seek medical advice' as we may need to change your biologic.
- Minor viral infections, e.g. coughs or colds. These usually do not require antibiotics, so you do not need to stop your biologic or contact us.
- 'Hypos' or low blood sugars if you're diabetic and using Etanercept.

Is there any cancer risk?

There isn't enough evidence of increased skin cancer with biologics, but it is highly recommended to wear high factor 50 sunscreen and check your skin for new spots or changes to your freckles or moles. Promptly report these to your GP. Please also comply with national cancer screening programmes and report any investigations to us.

When do I seek medical advice?

Biologics work against the immune system, so infections can occur. These can present in many ways - some are listed here:

- Fever, chills/sweats or feeling generally unwell (it is advisable to keep a thermometer at home).
- Shortness of breath.
- Pain and frequency on passing urine (water infection.)
- Chickenpox/shingles or if you come into contact with someone who has these.
- Signs of tuberculosis, which include persistent/productive cough, fever, weight loss or night sweats.

Other symptoms to report include:

- A red, inflamed area around the injection site larger than a 50p coin.
- Increased muscle ache, pains or joint swelling.
- Unsteady walking.
- Pins and needles or difficulty with movements.
- Changes to your vision, mood or speech.
- Chest pain, coughing up blood or warmth, redness and pain to your leg.

If such symptoms occur:

1. STOP your biologic.
2. Report symptoms promptly to your GP or 24-hour primary care centre **on the same day**.
3. Inform your GP if you are, or have been taking a biologic, even if you stopped the medicine up to six months ago.
4. If given a course of antibiotics, complete the full course and inform us at your next appointment. You do not need to ring us.
5. Only after this, you may restart your biologic drug, provided all your symptoms of infection have gone away. Ideally wait for another five to seven days, to ensure there is no reoccurrence of symptoms.

How do I prevent infections?

- Stop smoking. This drives the rheumatic disease, prevents the biologic from working and increases the risk of heart problems, amongst many other diseases.
- Maintain good dental hygiene with regular dentist check-ups.
- Maintain high standards of personal and food hygiene when storing, handling and preparing food.
- Avoid soft cheese (feta and goat's cheese), blue cheese, pate, unpasteurised milk/its products, raw eggs, undercooked meats.

Surgery advice

Biologics need to be stopped for a period of time before and after any surgery, including major dental work. Contact us **as soon as possible** for advice, as some medication needs to be stopped for a significant amount of time.

Vaccines:

- Avoid live vaccines, e.g. Varicella zoster, mumps/measles/rubella, oral polio, yellow fever. In certain situations, if a live vaccine is required, please discuss this with the rheumatology team.
- Stay up to date with non-live vaccines, e.g. COVID-19 vaccines, annual flu vaccine, one-off pneumococcal vaccine. **Ideally have these four weeks before starting biologics.**
- **Rituximab patients.** Receive all vaccines four weeks before your infusion and six months after the last infusion.

- Ideally avoid handling nappies or animal waste of infants or pets vaccinated against live vaccines for at least four weeks following the administration of the vaccine. Or consider wearing gloves during this time.

Travel advice

Before travelling, be aware of common illnesses and required vaccines for countries you wish to visit. Travelling to places such as tropical Africa or South America is inadvisable as you cannot receive the yellow fever vaccines with biologics.

Consider malaria protection through appropriate medicines and insect bite protection from your local pharmacy and maintain good personal, food and water hygiene.

If self-injecting: An airline letter from us is needed and a travel sharps bin from Homecare. Store your biologics in a cool bag within your cabin bag.

Contraception

Women of child-bearing age should use effective contraception, and for a variable time after stopping biologics.

Family planning

Pregnancy and breast feeding is not advised whilst receiving biologics. If you are planning a pregnancy, contact us in advance so we can advise on the best biologic for you. If you do become pregnant during treatment, don't worry, just contact us as soon as possible. If biologics are continued later in pregnancy, live vaccines should be avoided in the baby until six months old.

What follow up will I receive?

Three monthly appointments for the first year and then six monthly as a minimum. Each time you should expect to receive a blood test and a joint examination to monitor your progress. Failure to attend for follow-up appointments or blood tests will result in your biologic prescription being stopped - **this is a requirement from the NHS.**