

# Your guide to the Rheumatology Department

## Rheumatology

Information for patients and carers

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Caring for you

## Rheumatology Service

Our service aims to give patients with rheumatology conditions the best possible care. This includes education, information and support to help them carry out daily activities.

### Rheumatology patient advice line

You can contact the rheumatology nurses by calling 01925 662458 if you need help with your rheumatological condition or medications.

The answerphone is available Monday to Friday, from 7am to 9am. The advice line is closed on bank holidays.

This is not an emergency service and there may be delays in our response.

For any urgent issues, please contact NHS 111 or your GP.

The advice line is particularly for patients who do not have an appointment with a rheumatology team member within the next 2 weeks.

You will need your:

- name
- phone number
- date of birth
- reason for your enquiry

If you are calling on behalf of someone else, they must be present each time you call to provide consent.

We can only advise on issues relating to rheumatological conditions or medications.

### **We can help you if you are:**

- ✓ letting us know if your joint symptoms are getting worse
- ✓ asking about increasing or reducing your rheumatology medication
- ✓ switching your rheumatology medication (only if previously discussed with a team member)
- ✓ changing, or giving an update, about your Planned Investigations Unit (PIU) / Halton Day Unit appointment (if you have the contact number for PIU, and your appointment is within the next 2 days, please call them directly)
- ✓ telling us if you are struggling to reduce your steroids
- ✓ asking for guidance about rheumatology medications if you have an infection, including COVID, or have been in contact with someone with chicken pox or shingles

- ✓ letting us know that you have had your blood tests taken (we will only ring you with your results if there is a problem)
- ✓ requesting further blood forms

### **We cannot help you with:**

- ✗ emergencies - it is only for rheumatology advice
- ✗ general medical queries **not** related to your rheumatological condition (e.g. chest pain, leg swelling, shortness of breath, dental issues, dizziness, loss of consciousness, or for advice following an accident or injury)
- ✗ pain control – please speak to your GP about this
- ✗ discussing flu-like/COVID symptoms – these need to be discussed with your GP
- ✗ discussing treatment of conditions such as chicken pox or shingles
- ✗ discussing if you have any issues with your local pharmacy or home care company
- ✗ queries about appointments – please call the Appointments Team on 01925 662335

Please note:

- ✗ If your appointment with the Rheumatology Service is within the next 7 days, we will not call you back.
- ✗ If you have seen your GP and they are sending a referral to the Rheumatology Service, there is no need to ring us. An appointment will be made for you soon.

## **Biologic medication deliveries**

If your delivery of biologic medications (such as abatacept, baricitinib, certolizumab, etanercept, golimumab, secukinumab, tocilizumab, tofacitanib, ustekinumab) is late and you would like to chase it up, please contact the home care company directly.

### **Homecare provider contacts**

- Alcura: 0800 980 0680
- Healthnet Homecare: 0800 083 3060
- Sciensus: 0333 1039 499
- Lloyds: 0345 2636 123

Please do not call the advice line, or the secretaries, to chase deliveries.

## **New biologic prescriptions**

If you need a new prescription, please call the advice line on 01925 662458.

## **New disease-modifying anti-rheumatic drug (DMARD) prescriptions**

If you need a new DMARD prescription (methotrexate, sulfasalazine, leflunomide, azathioprine, mycophenolate) please call the advice line on 01925-662458.

## **Frequently asked questions**

### **When is my next appointment?**

You will have been told at your clinic appointment. If you have not received an appointment 2 weeks before your appointment is due, please call 01925 662335.

### **What should I do if I have medication side effects?**

If you think they are related to your rheumatological condition or treatment and they are not settling, you can stop the medication, but please contact the advice line too. If they seem unrelated, please contact your GP.

### **Do I stop my DMARD treatment if I am having surgery?**

There is no convincing evidence that continuing these medications affects surgery. In fact, coming off them can cause flares in your arthritis, which can be more problematic. Therefore, we recommend you stay on your drug treatment (excluding biologics and methotrexate, which will need to be stopped). However, if you are advised to stop it before surgery, then we would suggest 2 weeks before.

### **Do I stop taking methotrexate if I am having surgery?**

We recommend you stop 2 weeks before your surgery. Your wound must be completely healed before restarting your treatment.

### **Do I stop taking leflunomide if I am having surgery?**

We recommend you stop 10 weeks before your surgery as it stays in your body for a long time after taking it. Your wound must be completely healed before restarting your treatment.

### **How long do I need to be off my biologic medication before having surgery?**

For injectable biologics we advise:

- pausing treatment for 1 dose before any surgery
- restarting treatment 2 to 4 weeks after surgery

Your wound must be completely healed before restarting your treatment. Please contact us if you are on a biologic infusion (e.g. infliximab or rituximab).

### **What should I do if I have started on a new DMARD treatment and my prescription has nearly run out?**

Please read the shared care information leaflet, which you should have received when you started the medication. We will give the first two prescriptions, each for 12 weeks. Please call the advice line on 01925 662458.

### **How often do I have my bloods checked on my treatment?**

Monitoring is different for each medication. Please check the shared care leaflet or the blood forms you were provided with when you started the medication.

For most DMARDs, the following is common:

- every 2 weeks for the first 6 weeks of treatment
- then monthly for 3 months
- then every 3 months for the duration of treatment.

For biologic medications:

- it is normally monthly for the first 3 months of treatment
- then every 3 months for the duration of the treatment.

Once your GP takes over the shared care of your DMARD medication, they will advise on frequency.

### **What should I do if my GP has told me there is a problem with my bloods and that I need to speak to my specialist?**

The action taken depends on the problem. We usually recommend coming off medication for 2 weeks, repeating bloods tests and adjusting treatment if needed. If your results are abnormal, the nursing team will let you know if you need to do anything.

### **When should I have my next blood test after a DMARD dose increase?**

Usually, at 2 and 4 weeks after increasing the dose.

### **Can my DMARD blood monitoring frequency be reduced if I have been stable for a long time?**

Please follow the guidance from your drug education clinic appointment.

## **What vaccinations can I safely have?**

Avoid live vaccinations (e.g. yellow fever, MMR and varicella). We recommend flu, COVID and the non-live version of the Shingles vaccine (shingrix).

## **Can I get my bloods / X-ray result?**

Unfortunately, we can't give feedback individually on the results of all blood / X-ray tests to our patients. If there is anything abnormal in your blood tests or X-ray, the Rheumatology Service will get in touch with you and/or your GP. If you don't hear from us, you can assume the results were satisfactory.

## **I had an ultrasound / MRI scan but have not had results?**

It can take a couple of weeks for it to be reported. Your consultant will contact you once the report is received. If you haven't heard anything after four to six weeks, please leave a message with your consultant's secretary.

## **What should I do about my treatment when I go on holiday?**

- Take a copy of your last clinic letter (or repeat prescription list if your GP is supplying the medication) with you for information.
- If you are taking tablets, these should be taken with you on holiday and continued as normal.
- If you are on an injection treatment, this can also be taken with you in your hand luggage using a cooling bag.
- If you are flying, please contact us if you are taking methotrexate injections and we will supply a letter.
- If you are taking injectable biologic medications, please contact the home care company and they will supply the relevant letter. Needles can be taken through security at airports, if you have the necessary letter. Take it through security in its normal container, separate from your other hand baggage, and refrigerate the medication once you reach your destination.

## **What should I do about the treatment I am receiving if I am pregnant or trying to get pregnant?**

If you wish to get pregnant, discuss your plans at your clinic appointment with your rheumatologist, so medications can be adjusted, if needed. If you think you may be pregnant, please contact your GP surgery or the advice line.