Contact details

PIFU- LTC Telephone number: 01225 821611

Rheumatology Advice Line: 01225 821611

Rheumatology Appointment Line: 01225 473401

Royal United Hospitals Bath NHS Foundation Trust
Combe Park, Bath BA1 3NG
01225 428331 www.ruh.nhs.uk

Please contact the Patient Support and Claims Team (PCST) if you require this leaflet in a different format, or would like to feedback your experience of the hospital.

Email ruh-tr.psct@nhs.net or telephone 01225 825656.

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Patient Initiated Follow Up Long Term Condition (PIFU- LTC)

Rheumatology Department



Rheumatology PIFU-LTC

Information for patients

• This leaflet provides information for patients who have attended a rheumatology outpatient clinic at the Royal United Hospital and have been offered a “patient initiated follow-up for their long-term condition” appointment. This is also known as PIFU (pronounced *“PI-FOO”)* for short.

• It explains what PIFU-LTC is, how it works, and gives you the information you need to contact us to arrange a follow up appointment for yourself. We hope you find it helps you feel confident and in control of your own follow up.

• If you would like further information, or have any particular worries about PIFU-LTC, please do not hesitate to ask a member of the clinical rheumatology team.

What is patient initiated follow-up PIFU-LTC?

• PIFU- LTC is for patients with stable long-term health conditions.

• It allows you to arrange your follow up appointments as and when you need them. Instead of having frequent hospital appointments booked routinely e.g. every year, you can request them when you need them.

• You will still have a hospital appointment booked every 1-2 years by default.

• This puts you in control of your hospital follow up. It means spending less time attending hospital appointments when you don’t need them, but still gives you access to support when you need it.

Medication Enquiry	
Does your query relate to a medication, medication-related side-effect, medical script, or being unclear about the instructions of a prescribed medication?	
What should you do: Call the Rheumatology Advice Line and leave a message saying you are a PIFU-LTC patient with a ***question regarding medication.***	
Action: We will aim to contact with you within 2 working days.	
Examples	**Examples**
I have noticed a side-effect of a medication.	Call back from Specialist Nurse
I want to change some/change dose of my medication.	Call back from Specialist Nurse
My disease is stable. Can I reduce my medication?	Call back from Specialist Nurse
I have been prescribed a rheumatological medication and have some more questions.	Call back from Specialist Nurse

Occupational Therapy or Physiotherapy

Does your enquiry relate to your ability to work, to sleep, your energy levels, your ability to manage daily tasks or your mobility/balance?
Where you feel it isn't a specific disease flare that is causing your issue, an Occupational Therapist or Physiotherapist may be able to offer you relevant advice and support.

What should you do:
Call Rheumatology Advice Line and leave a message.
Please mention you are a "***PIFU-LTC patient needing a Therapies Telephone Review***

Action: We will be in contact with you within 10 working days

Examples	What is likely to happen
You are struggling to stay in work or have recently had to stop work due to your rheumatology condition.	Telephone review with therapy team (Physiotherapist or Occupational Therapist)
You are struggling with a recent change in your sleep/energy/fatigue management due to your rheumatology condition.	Telephone review with therapy team (Physiotherapist or Occupational Therapist)
You have noted a recent decline in your mobility/ability to keep active and exercise/ability to perform daily activities, which appears to be related to your rheumatology condition.	Telephone review with therapy team (Physiotherapist or Occupational Therapist)
You have noted a recent decline in your balance or you have started to fall, which appears to be related to your rheumatology	Telephone review with therapy team (Physiotherapist or Occupational Therapist)

Why offer this type of follow up?

There are a number of benefits to PIFU-LTC.

- We hope reducing time and money spent attending unnecessary appointments will improve your overall experience.
- Freeing up appointments means we can reduce the waiting times for other people who need one, enabling them to be seen more quickly.
- It will also help us to cut down our carbon footprint by reducing the number of unnecessary journeys made to our hospital.

How will I know if I'm suitable for PIFU-LTC?

The rheumatology team will tell you if your condition is now suitable for PIFU-LTC. It is entirely your decision whether you move to PIFU-LTC or continue with more frequent appointments. Your clinician and this leaflet are there to help you decide which system you prefer

How does patient initiated follow up work?

- If PIFU-LTC is suitable for you, we will add your name to a PIFU-LTC appointment list.
- Rheumatology patients with PIFU-LTC follow up will have their next routine appointment booked for 1- 2 years' time.

•Rheumatology patients taking “Biologic” medications (including most injectable medications but not injectable Methotrexate) will have a routine appointment after 1 year.

• Rheumatology patients not taking “Biologic” medications will have a routine appointment after 2 years.

• You will be able to contact us directly to arrange an earlier appointment if you feel you need it.

• If you do not contact us then we will see you 1-2 years after your last appointment.

When should I call for a PIFU-LTC appointment?

You should call if you experience worsening of your symptoms and think you need to be seen by a member of the Rheumatology team.

Symptoms requiring an appointment might include:

- Flare that has not settled as with usual self-management strategies e.g. anti- inflammatory medications, exercises and stretches
- Flares that are happening more frequently than usual
- Flares that are lasting longer than usual or affecting more areas of the body e.g. more joints

Infection Does your query relate to a new infection?	
What should you do: Call the Rheumatology Advice Line and leave a message saying you are a PIFU-LTC patient ***with a new infection.***	
Action: We will be in contact with you within 2 working days.	
Examples	**Examples**
I have a new Covid diagnosis.	Call back from Specialist Nurse or doctor
I have a new infection (i.e. urinary tract infection, pneumonia, cellulitis **or any other non-Covid related infection**).	Call back from Specialist Nurse
I have recently been prescribed antibiotics.	Call back from Specialist Nurse
I have recently been admitted to hospital with an infection.	Call back from Specialist Nurse

When is my next appointment?	Please call the Rheumatology Appointments line **01225 473401**
When is my medical imaging test (e.g x-ray) appointment?	Please contact the Radiology Department through the hospital switchboard.
I want a medical review for my medical condition, and I am currently stable	Call back from Specialist Nurse within 48 hours
I am on a PIFU pathway and wish to have an earlier review than scheduled (and am not experiencing a disease flare)	Call back from Specialist Nurse within 48 hours
I need to reschedule my existing appointment	Please contact the Rheumatology Appointments line **01225 473401**
I no longer want to be a part of the PIFU pathway	Please contact your Consultant's Secretary (email address at the bottom of your clinic letter) and let them know your decision

Issues that won't usually require an appointment:

- First flare of symptoms- this can usually be managed using self-help strategies or by speaking to one of our nurses on the telephone
- Requests for medications- this can usually be dealt with by the administrative team
- Requests for appointments or test results- this can usually be dealt with by the administrative team

Further examples of common patient symptoms and concerns and our usual actions can be found at the end of this document "Common patient scenarios".

PIFU-LTC appointments and our Rheumatology advice line are not a replacement for urgent medical advice. If you require urgent medical advice, you should contact your GP, NHS 111, your local walk-in centre or, if you are really unwell, your local Emergency Department (A&E).

How do I request a patient initiated follow-up appointment?

To request an appointment please follow these steps:

1. Call our Rheumatology Advice Line on **01225 821611**.
2. The telephone is manned Monday to Friday 9am to 3pm. You will need to leave a message on the answerphone.
3. Please say:
    a. You are a "PIFU-LTC patient"
    b. Your name and date of birth
    c. You require an appointment.

d. A brief description of your symptoms so we know why you are requesting an appointment.

What happens next?

Our administrative team will listen to your message.

If you report symptoms that require a clinic appointment we will book one for you. Your appointment should be within 10 working days of your call. You will receive either a telephone call or text message confirming the time and date of your appointment.

If you describe symptoms that might be better dealt with over the telephone a phone call with one of our nurse specialists will be arranged. Your phone call should be within 1-2 working days of you contacting us.

Frequently asked questions

• How long will I have to wait before I receive an appointment?

Because you are on the PIFU-LTC pathway, if you need to be seen, you will be given priority and booked in as soon as possible. We will aim to see you within 10 working days of you contacting us.

• I can't wait 10 working days for an appointment

If you cannot wait 10 working days for an appointment, please request a call back from the nursing team instead of an appointment.

If you have an emergency issue e.g. chest pain, severe shortness of breath please contact your GP, 111 or 999. We are unable to offer an emergency service.

New Diagnosis or Medical Administration Question

Does your query relate to updating the Rheumatology team regarding a new diagnosis or something that may change your current management?
Does your query relate to when you are next due for an appointment, medical investigation, or recent test result?

What should you do: Call Rheumatology Advice Line and leave a message
Please mention you are a "***PIFU patient with a non-clinical question" and then leave a message with a description of your query***

Examples	**What is likely to happen**
I have an upcoming surgery/procedure	Call back from Specialist Nurse within 48 hours
I have a new diagnosis, i.e. I was diagnosed with prostate cancer, pneumonia/UTI or was recently admitted to hospital.	Call back from Specialist Nurse within 48 hours
I have a result my doctor asked me to update them about a result/condition	Please email the result to the relevant medical secretaries. We will be able to forward the result to the relevant clinician

Disease Flare	
Does your query relate to a disease flare/progression of symptoms relating to your underlying rheumatological condition?	
What should you do: Call the Rheumatology Advice Line and leave a message saying you are a PIFU-LTC patient with ***a disease flare up.***	
Action: A nurse will call to discuss your symptoms (within 48 hours) and may organise a face-to-face appointment within 10 working days if needed.	
Examples	**Examples**
I was last seen 6-12 months ago; I have joint pain and I am struggling to go to work.	Face-to-face appointment within 10 working days
I was recently prescribed prednisolone by my doctor, and since I stopped it, my joint pain has returned.	Face-to-face appointment within 10 working days
My joint/joints have been swollen for more than 1 week.	Face-to-face appointment within 10 working days
I have newly swollen joints and a disease flare but am unable to attend a face-to-face appointment.	We will organise a telephone appointment within ten working days

• I left a message but haven't heard anything back

We aim to answer all messages within 1-2 working days. Sometimes we are unable to reply to messages e.g. if the message is unclear or no name has been left. If you have not received a response within 2 working days please call us again.

• What if I don't need to call you between appointments?

You will stay on our appointments waiting list and be booked for a follow up appointment 2 years after your last appointment.

• What if I don't know if I need an appointment?

A list of common symptoms and scenarios is found at the end of this leaflet. This should help you decide whether to contact us.

Further frequently asked questions are available at: https://www.ruh.nhs.uk/rnhrd/patients/services/rheumatology/documents/RNHRD_Rheumatology_FAQ.pdf

You can also speak to your GP if you have symptoms you are worried about.

• Will I stay on a PIFU-LTC pathway forever?

Some patients will remain on the pathway indefinitely. Other patients may return to more regular follow up appointments. For example if your condition or your treatment changes you may need to be seen more regularly. You can always ask to return to normal follow up appointments if you no longer wish to be on a PIFU-LTC pathway.

Self-management advice

The following websites have useful information about managing your symptoms between appointments

Rheumatoid Arthritis

https://nras.org.uk/smile/

Ankylosing Spondylitis

https://nass.co.uk/managing-my-as/my-as-my-life/

PMR

https://pmrgca.org.uk/

Rheumatology patient podcasts

https://www.birdbath.org.uk/podcasts

Clinical Scenarios PIFU-LTC

If you are on a PIFU-LTC pathway and have a concern about your rheumatological condition, please **contact us on 01225 821611.**

Please refer to the following **example scenarios,** which describe common issues patients contact us with and how we usually manage these.

When you leave a message with us, you can use one of the descriptions listed overleaf if it helps describe your concern. If none of the scenarios describes your concern, please describe it to the best of your ability, and we will do our best to triage your concern accurately and efficiently.

- **Call the Rheumatology Advice Line if you have a concern: 01225 821611**
- **Leave an answerphone message with the following details:**
    - Name and Date of Birth
    - Best contact number
    - You are on the **PIFU-LTC PATHWAY**
    - Describe concern/clinical scenario

PLEASE NOTE: If you do not identify yourself clearly OR state that you are on a PIFU-LTC pathway; we may not be able to organise your care within 10 working days