



Haematology Patient-Initiated Follow-Up (PIFU)

Lymphoma

What is Patient-Initiated Follow-Up (PIFU)?

Not all patients with long-term health conditions such as low grade lymphoma need regular follow-up with their hospital team. Many patients will never require treatment. Regular clinic visits, often a source of anxiety, do not prevent the condition from progressing. It is more important that patients can access care promptly when they need it. This is the purpose of patient-initiated follow-up (PIFU). Rather than being offered regular clinic appointments with a doctor or specialist nurse at fixed time points, PIFU patients can contact the team to arrange an appointment if/when required.

What are the potential benefits of PIFU?

PIFU puts patients in control of their own care and provides direct access to the hospital team when needed. This is often more convenient for patients. It reduces unnecessary travel to the hospital and time spent waiting in clinic for routine follow-up appointments. It means concerns can be acted on quickly, rather than waiting to discuss them in a planned appointment. PIFU also frees up the consultants to be available to see patients in need of review in a timely fashion.

Are all patients with low grade lymphoma suitable for PIFU?

Only patients who have not needed treatment and in whom there is no clinical concern of progression, are eligible for the PIFU service. You will have been monitored in clinic for at least 1 year. Your named consultant will also need to agree that this service is appropriate for you as an individual.

How does PIFU work?

Once a patient has been identified as suitable for PIFU by their consultant, this will be discussed with them by an appropriate member of the haematology team, be that a doctor, specialist nurse or physician associate. Patients being transferred to PIFU will receive this information leaflet and a contact details card for the specialist nursing team, which are also stated in this leaflet. We will write to your GP to explain that you will be managing your appointments using PIFU.

When should I contact the specialist nursing team?

You should call the haematology specialist nursing team if you have any of the following symptoms, which persist for at least 2 weeks:

- New or growing lumps, bumps or swollen glands

- Unexplained weight loss, either rapid or amounting to 10% of your body weight

- Recurrent drenching night sweats requiring you to change your clothes or bedding

- Recurrent fevers in the absence of infection

- Other symptoms which are worrying you and causing you to think your lymphoma may be active

How do I contact the specialist nursing team?

The specialist nurses are available Monday-Friday 08:30-17:00 (excluding bank holidays) on the following numbers: 01904 72 5815 (York) and 01723 34 2976 (Scarborough). If you get an answerphone, please leave a message with your name, contact number and ideally hospital number and your call will be returned.

What will happen when I contact the specialist nursing team?

A specialist nurse will discuss your concerns and symptoms with you and unless they feel another route would be more appropriate (eg A&E for an emergency), they will book you in for an urgent review in your consultant's clinic. Appointments may be up to 28 days in the future, but will be sooner if clinically needed.

What will happen following my PIFU appointment?

Following your appointment, the doctor or specialist nurse will discuss with you whether to remain under PIFU or whether to go back to regular appointments.

When is it not appropriate to contact the specialist nurses?

If you require urgent medical **advice**, you should either contact your GP, or call NHS 111. If it is an emergency, you should dial 999 or attend your local Emergency Department (A&E). For all other medical concerns, your GP remains your first point of contact.

What will happen if I do not need to contact the team?

Whilst we are only using the PIFU service for patients who do not require regular follow up, we will contact you to arrange an appointment if you have not contacted us requiring a PIFU appointment after a fixed period of time, usually 10 years.

Feedback

We appreciate and encourage feedback. Please note we may be in touch in the future to ask about your experience.

① If you have further concerns about your condition, please contact:
Child Development Centre, York Hospital, Wigginton Road, York, YO31 8HE
Telephone: 01904 726539.

Patient Advice and Liaison Service (PALS)

We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or
email yhs-tr.PatientExperienceTeam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you require this information in a different language or format, for example Braille, large print, Easy Read or audio, please ask the staff who are looking after you.

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