



Information for patients, relatives, and carers

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# Immune Thrombocytopenia (ITP) Haematology Patient-Initiated Follow-Up (PIFU)

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

Not all patients with immune thrombocytopenia (ITP) need regular follow-up with their hospital team. Many patients will never require treatment and regular clinic visits are unlikely to coincide with a platelet drop and do not prevent the platelets dropping. Instead, it is more important that patients can access care when they need it, and 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 or 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 and 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.

## Are all patients with immune thrombocytopenia for PIFU?

Your platelet count will need to be safe and stable following either no or limited treatment. You will have been monitored in clinic for at least two years. Your named consultant will 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:

- Increase in unexplained bruising
- New or increased bleeding from any part of the body
- Planned operation or procedure when the team carrying out the procedure are not planning a blood count check prior. This includes dental extractions and root canal treatment (but not cleaning or fillings).
- If you are planning to start a new medication known to increase the risk of bleeding (for example anti-platelet or anti-coagulant), please ensure the person prescribing the medication is aware of your ITP and the need to check your blood count before commencing these treatments. If required, you or they can contact our team to discuss this.

## **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 arrange for an urgent blood count (within 24 hours). If required, you will then be reviewed by a doctor the same day and/or a follow up appointment made in the consultant clinic. If the specialist nurse is concerned you are experiencing heavy bleeding or bleeding in a critical site, they may ask you to attend A&E.

## **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.

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① If you have further concerns about your condition, please contact: Outpatient Services, York Hospital, Wigginton Road, York, YO31 8HE or telephone: 01904 726400.

## 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](mailto: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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