



Patient Initiated Follow-Up (PIFU) for patients with lymphoma

A guide to supported self-management for patients with a lymphoma diagnosis, from the Haemato-oncology Specialist Nurse Team

You have been referred to Patient Initiated Follow-Up (PIFU), as you have either:

- completed your lymphoma treatment; or
- been told that you do not currently need treatment.

With PIFU, instead of having regular follow-up clinic appointments, you can contact your clinical nurse specialist to discuss any worries or concerns you may have.

This leaflet will help you decide when or if to contact your clinical nurse specialist for advice.

When should I call?

Lymphoma can present in many ways. Call the Cancer Care Line and speak to your clinical nurse specialist if you experience any of the following.

- Any changes that continue for more than 2 weeks.
- New persistent lumps or bumps, or swollen lymph nodes.
- Unexpected rapid weight loss.
- Recurrent drenching night sweats or unexplained fevers that keep happening.
- Other symptoms which are worrying you, causing you to think your cancer may have returned.

What are the benefits of PIFU?

- Some people find coming to regular appointments a source of anxiety. PIFU means that you do not have to come to hospital for any unnecessary appointments.

- It also means that we can pick up problems early and act quickly, rather than waiting to discuss them at one of your routine appointments.
- If you need them, we can quickly arrange urgent appointments, scans, and blood tests. You do not have to wait for your next routine appointment.

Please remember that you are still under the care of Haematology, and you can discuss any concerns you have with your nurse specialist at any time.

What is supported self-management?

Another term for Patient Initiated Follow-Up is supported self-management.

Some patients are on Active Surveillance (also known as 'Watch and Wait') for a slowly progressing lymphoma (low grade). These can sometimes take many years to progress, and some never need treatment. Supported self-management puts you in control. You are able to call your clinical nurse specialist directly to discuss your concerns. We can book you an appointment if you need one.

What happens when I contact my clinical nurse specialist?

Please call your clinical nurse specialist via the Cancer Care Line. A member of staff will answer the phone, and book you the next available appointment for your clinical nurse specialist to call you back (usually within 24 hours).

- **Cancer Care Line**
Telephone: 01227 868666
Monday to Friday 9am to 5pm and Saturday to Sunday 8am to 5pm

When you speak to your clinical nurse specialist, they will discuss your concerns with you and they may recommend one of the following.

- A clinic appointment to see us at the hospital.
- Blood tests or a scan.
- For you to make an appointment with your GP.
- Reassure you that no further action is needed.

Use this time to ask any questions or raise concerns.

I'm feeling more emotional than usual, is this normal?

Yes. It is normal to feel emotional for a while after your treatment has ended, and recovery can take time. You can call your clinical nurse specialist to discuss anything that is worrying you, such as:

- low mood, depression, or feelings of isolation
- money worries
- problems related to your diagnosis or treatment; or

- going back to work.

I'm always anxious that my lymphoma may return

It is natural to feel anxious that your lymphoma will return. We recognise that this can make you feel very uncertain about the future and lead to difficulties in 'getting on with life'. Some people find it useful to have further support in dealing with these feelings. Please call the Cancer Care Line if you feel that you would benefit from some extra help or reassurance.

Further information and support resources

- Lymphoma Action (<https://lymphoma-action.org.uk/>)
- Macmillan Cancer Support (<https://www.macmillan.org.uk/>)
- Blood Cancer UK (<https://bloodcancer.org.uk/>)
- Patient Initiated Follow Up: giving patients greater control over their hospital follow-up care. NHS England (<https://www.england.nhs.uk/outpatient-transformation-programme/patient-initiated-follow-up-giving-patients-greater-control-over-their-hospital-follow-up-care/>)

Contact details

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This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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