

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

Now that you have either completed your lymphoma treatment, or you have been told that you do not currently need treatment, you have been referred to Patient Initiated Follow-Up (sometimes known as PIFU). Instead of having regular follow-up clinic appointments, you will be able to contact your clinical nurse specialist when you need to discuss any worries or concerning symptoms you may have.

This information sheet is designed to help you decide when or if to contact your Clinical Nurse Specialist Team for advice.

When should I call?

Lymphoma can present in a number of ways. You should call the Cancer Care Line if you notice any changes that continue for **more than two weeks**. You should telephone the Cancer Care Line and speak to your clinical nurse specialist if you experience any of the following.

- 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.
- We can arrange urgent appointments, scans, and blood tests quickly if you need them, 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 (some people call this '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, and you are able to call your 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 on 01227 86 86 66**, Monday to Friday 9am to 5pm and Saturday to Sunday 8am to 5pm. 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).

When you speak to your clinical nurse specialist, they will discuss your concerns with you and then 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 hospital staff any further questions or raise concerns.

I am 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 am always anxious that my lymphoma may return

It is entirely 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 some additional support in dealing with these feelings. Please let us know if you feel that you would benefit from some extra help or reassurance, by calling the Cancer Care Line.

Further information and support resources

- **Lymphoma Action**
Web: lymphoma-action.org.uk/
- **Macmillan Cancer Support**
Web: www.macmillan.org.uk/
- **Blood Cancer UK**
Web: bloodcancer.org.uk/
- **Patient Initiated Follow Up: giving patients greater control over their hospital follow-up care. NHS England**
Web: 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

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation