

Personalised follow-up after treatment for lymphoma

Information for patients

What is it?

Personalised follow-up involves tailoring how we see you after treatment to suit your individual needs and wishes.

Personalised follow-up is made up of two pathways; supported self-management and professional-led:

- Patients at low risk of recurrence and late effects do not need to attend regular appointments, and instead, on the supported self-management pathway, will trigger the need for an appointment by their own concern.
- Patients at high risk of recurrence will continue to receive routine follow-up appointments with the medical or nursing team on the professional-led pathway.

A key element of personalised follow-up involves ensuring patients have the necessary support and education to help them take charge of their care and wellbeing.

This is especially important for patients on the supported self-management pathway who will need to know when they should get in touch with their specialist team.

Those on the professional-led pathway will also need to be aware of this information, as although regular follow-up appointments continue, it is important that patients do not delay reporting concerns until their next appointment.

What are the benefits?

Evidence is available demonstrating that for well people after treatment, there is no advantage to scheduling appointments at fixed intervals where you have to attend a hospital appointment.

Research has also shown that regular appointments do not help prevent cancer returning and specifically in identifying new problems. Instead, regular follow-up appointments can actually increase anxiety for patients unnecessarily.

Some patients don't report any concerns if they have a routine appointment not too far away, whereas being on a supported self-management pathway would prompt you to get in touch with concerns sooner.

How does it work?

Once you have finished treatment you will attend an end of treatment clinic appointment with a doctor and haematology nurse specialist (HNS).

All patients will receive regular follow-up appointments for the first two years after treatment, however, at your end of treatment clinic appointment, your consultant and HNS will advise you on whether they feel you are likely to be suitable to enter onto the supported self-management pathway at the end of this two years.

At the final appointment of your two-year follow-up post treatment, your consultant and HNS will advise you whether you are suitable for the supported self-management pathway or should remain on the professional-led pathway.

If you have been identified as suitable for the supported self-management pathway, you will then be given the opportunity to decide if you wish to progress as per the clinical team's advice. Should you wish to remain on the professional-led pathway, this will be made possible.

Around two weeks after the appointment with your consultant and HNS, you will receive a telephone call from the HNS. In advance of this call, the HNS will request that you complete a Holistic Needs Assessment (HNA), which helps us to identify any particular concerns or needs you have, and then we can take steps to help you with these.

During the telephone call, the HNS will go through your completed HNA and with you develop a care plan. The HNS will go through long-term symptoms, signs of recurrence and health and wellbeing advice.

An end of treatment summary will be created and sent to both you and your GP. Your treatment summary provides information about your diagnosis and treatment(s), as well as how your follow-up care will be organised.

What are the risks?

Some people think that regular follow-up appointments at the hospital can help pick up the recurrence of lymphoma, but there is no evidence to support that. It is seldom identified when the patient attends an outpatient appointment.

What are the alternatives?

If you have specific concerns or health-related issues that make you feel like the supported self-management pathway is unsuitable for you, you can continue to have regular follow-up appointments.

As outlined above, during your appointments, the consultant and HNS will outline whether you are suitable for the supported self-management pathway, however, you will make the choice on whether you wish to take this advice and move onto this pathway.

Who do I contact if I need advice or support?

Please contact the HNS on 01623 622515, extension 3081 if:

- You have any concerns about how to manage your health and wellbeing following your treatment.
- You develop any new signs and symptoms that you have been advised about (night sweats, weight loss, lumps and bumps).
- You have a recurrence of signs and symptoms you have had in the past.

We will review the situation with you and determine what next steps need to be put in place for you. If you are required to have an appointment, we will arrange for you to be seen within two weeks.

Contact details

Haematology Nurse Specialists; telephone 01623 622515, extension 3081.

Further sources of information

NHS Choices: www.nhs.uk/conditions
Our website: www.sfh-tr.nhs.uk

Lymphoma Action

Helpline: 0808 808 5555
Website: www.lymphoma-action.org.uk

Macmillan Cancer Support

Helpline: 0808 808 000
Website: macmillan.org.uk

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

King's Mill Hospital: 01623 672222

Newark Hospital: 01636 685692

Email: sfh-tr.PET@nhs.net

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

This document is intended for information purposes only and should not replace advice that your relevant health professional would give you. External websites may be referred to in specific cases. Any external websites are provided for your information and convenience. We cannot accept responsibility for the information found on them. If you require a full list of references (if relevant) for this leaflet, please email sfh-tr.patientinformation@nhs.net or telephone 01623 622515, extension 6927.

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