



York and Scarborough  
Teaching Hospitals  
NHS Foundation Trust

# Long-term follow-up for patients previously treated for Hodgkin Lymphoma

Information for patients, relatives and carers

① For more information, please contact:

The Haematology Teams

The Magnolia Centre, York Hospital,

Wigginton Rd, York, YO31 8HE

Telephone: 01904 725815

York Hospital Switchboard 01904 631313

The Macmillan Unit, Scarborough Hospital

Woodlands Drive, Scarborough, YO12 6QL

Telephone: 01723 34 2446

Scarborough Hospital Switchboard 01723 368111

<b>Contents</b>	<b>Page</b>
Why have I been given this leaflet? .....	3
What changes now? .....	3
Is there a chance I might relapse after the first two years?.....	3
Is it safe for me to be discharged? .....	4
Why would you follow anyone up after two years?.....	4
What should I look out for? .....	5
Contact details .....	6
Tell us what you think of this leaflet.....	7
Teaching, training and research .....	7
Patient Advice and Liaison Service (PALS) .....	7
Leaflets in alternative languages or formats .....	8

## **Why have I been given this leaflet?**

You finished your treatment for Hodgkin Lymphoma more than two years ago and achieved a complete remission at the time. We have been following you up in clinic, because there was a risk of relapse within the first two years after treatment. However, two years represent a positive milestone, as research shows relapse becomes very rare after this time.

## **What changes now?**

Most of our patients will be discharged at this stage. A small group of patients, for example those who have previously relapsed, may continue annual follow up with a doctor or a nurse.

## **Is there a chance I might relapse after the first two years?**

Yes, but the chance is very small. Research shows that only about one per cent of patients (one in 100) relapse in year three and four after treatment and even less after that. That is why we offer this information on what to look out for.

## **Is it safe for me to be discharged?**

Yes. Research shows that following up a patient in your situation routinely when well does not speed up recognition of relapse. In fact, frequent follow up may slow it down, as patients wait for their next follow-up appointment instead of seeking prompt medical help.

## **Why would you follow anyone up after two years?**

A small group of patients may have additional risk factors, such as requiring more than one line of therapy or proven relapse. This will be explained by your doctor at the time.

## What should I look out for?

Firstly, it is important to remember that most patients in your situation will never have to deal with their lymphoma again. Secondly, if you do have symptoms, please do not ignore them. See your GP in the first instance.

Symptoms of lymphoma include:

- drenching night sweats (having to change bedding and nightclothes)
- loss of appetite without obvious reason
- tiredness that interferes with your work or social life (it is normal to feel tired when you have had a busy day or stressful period in your life)
- loss of weight (when you are not trying to lose weight through dieting or exercise)
- lumps in your neck, under your arms or in your groin
- itching without a skin problem
- feeling like you did when you were first diagnosed.

## **Contact details**

Haematology clinical nurse specialists in York  
01904 72 5815

Haematology clinical nurse specialists in Scarborough  
01723 34 2446

Consultant secretaries:

York secretarial team                      01904 725777

Scarborough secretarial team   01723 712570

## **Tell us what you think of this leaflet**

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

The York Haematology Clinical Nurse Specialists on 01904 725815, The York Hospital, Wigginton Road, York, YO31 8HE.

## **Teaching, training and research**

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

## **Patient Advice and Liaison Service (PALS)**

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. 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 would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:

[www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/](http://www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/)

Owner	Dr Annika Whittle, Consultant Haematologist
Date first issued	August 2018
Review Date	June 2027
Version	3 (issued June 2024)
Approved by	Haematology MDT members
Document Reference	PIL1290 v3
© 2024 York and Scarborough Teaching Hospitals NHS Foundation Trust.	
All Rights reserved.	