

Lymphoma monitoring pathway

Information for patients

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This leaflet explains how the monitoring pathway works and has useful information and contact details for patients diagnosed with lymphoma.

What is the lymphoma monitoring pathway?

Previously, patients living with or after lymphoma have been seen at regular intervals by their clinical team for follow-up care. Some patients had found that attending these appointments can cause unnecessary anxiety and they are not always particularly helpful. Regular scheduled outpatient appointments may not result in any change to your management. In fact, your condition may alter in between the booked appointments and it is during this time that you really do need the input of the Haematology Team.

The lymphoma monitoring pathway will combine remote monitoring with clinic (telephone and face to face) follow-up appointments, in order to reduce the need for you to attend the hospital so regularly. The number of monitoring appointments will vary depending on where you are in your treatment journey and is adaptable to respond to your individual needs.

Meanwhile, for medical concerns not related to your lymphoma, your GP will remain your first point of contact.

How does this pathway work?

You will be advised by the Haematology Team if your condition is suitable for you to be monitored on the pathway. Your clinician will have discussed the process with you and given you this patient information sheet

You will be given a standard face to face follow-up appointment at 6, 12 and 24 months along this pathway.

Between these appointments, you can contact the service when or if you feel you need an appointment or wish to speak to someone.

- Patients with **high grade or Hodgkin lymphomas** will remain on the pathway for two years, and if your clinical condition remains stable during this time, you will be discharged.
- Patients with **low grade lymphomas** will remain on the pathway for as long as your condition is stable.

When should I call the service?

You should call if in between your scheduled appointments you experience new symptoms that may be due to lymphoma and need to be reviewed in the clinic. These symptoms may include:

- Swollen lymph nodes
- Drenching sweats (especially at night)
- Fever
- Itching
- Unexplained weight loss
- Unexplained discomfort / pain
- Fatigue
- Generally feeling unwell
- Difficulty shaking off infections
- Poor appetite

We will ensure you speak to a specialist nurse, who may be able to offer immediate advice or will arrange a clinic appointment for you, depending on your symptoms.

4 Easy steps to use the monitoring pathway:

- 1** Contact the clinical nurse specialists or Haematology Clinical Admin Team – **see contact details on cover.**
- 2** Your clinical nurse specialist will discuss your symptoms and decide if you need a clinic review.
- 3** An appointment date and time can then be made.
- 4** Attend your clinic appointment.

When contacting us, please have the following information available:

- ✓ Your full name and date of birth.
- ✓ Your hospital number and/or NHS number.
- ✓ A telephone number where we can call you during normal hours between 9am – 5pm.

Will you still be looking after me if I do not call for an appointment?

Yes, you will still have follow-up appointments booked at 6, 12 and 24 months alongside blood tests every three months. We will also arrange a follow-up appointment with you, depending on the results of your blood tests or if there is anything that needs discussion.

Can I change my mind about this style of follow-up?

If this type of monitoring doesn't suit you, just let us know and we will go back to booking haematology review appointments for you to attend at the hospital. Please discuss any concerns with a member of the team, who will be happy to help. The aim of this pathway is to enable you to access the service when you need it most while ensuring we are monitoring your health on a regular basis.

When not to call the Lymphoma Monitoring Pathway

If you require urgent medical advice you should contact your GP, NHS 111, your local Urgent Care Centre, or, if you are really unwell, your local Emergency Department (A&E).

To find out more about our Trust visit www.royalberkshire.nhs.uk

RBFT Haematology, February 2025. Next review due: February 2027.