

Follow-up appointments

This page explains what to expect from follow-up appointments and how to prepare for them. This information is relevant to people of all ages, although follow-up in children, teenagers and young adults may include some additional checks on development and growth.

On this page

Follow-up after treatment

What are follow-up appointments for?

Before follow-up appointments

What happens at follow-up appointments?

When will my follow-up finish?

Follow-up after treatment

Finishing treatment can bring a sense of uncertainty. You might feel anxious without the routine of frequent hospital appointments with your medical team. You may find this situation easier to manage if you have an idea of what's coming next.

After finishing **treatment** for lymphoma, you have an end-of-treatment appointment with your medical team. At this appointment, your consultant or nurse specialist talks to you about your physical, emotional and social needs. They might use questionnaires for this assessment. Your answers help them create a care and support plan that's specific to your individual needs. You might be given the opportunity to attend a health and wellbeing event, such as a **Live your Life workshop**, as part of your **recovery package**.

You should also be given a written treatment summary explaining what treatment you had, any long-term effects it might have, what symptoms of relapse (lymphoma coming back) or **late effects** to look out for after treatment, and who to contact if you notice them. If you haven't received a treatment summary, ask for one.

Your team will explain how you will be followed up in the future.

How often you have follow-up appointments depends on:

- the **type of lymphoma** you've had
- the **treatment** you've had
- your response to treatment
- the usual practice in your particular hospital or treatment centre.

Everyone's situation is different but, in general, you will be seen every 2–3 months when your treatment first ends. After an initial period of follow-up, which varies depending on your individual circumstances and your hospital's policy, your appointments may become less frequent. In fact, many hospitals are introducing a **self-management and remote monitoring** system, which means that instead of regular, pre-booked appointments, you arrange your own follow-up appointments as-and-when you feel you need one.

Whether you are on remote monitoring or a traditional follow-up schedule, you can contact your hospital team at any time. Don't wait until your next appointment if you are worried about your lymphoma.

Questions to ask about follow-up appointments

Below are some of the questions you may wish to ask your specialist about the follow-up process. Most hospitals routinely give out this information. If you haven't received it, ask for it.

You should have a contact number for your team. If you don't have it, or you're not sure which number to use, ask.

- How is follow-up organised?
- What does follow-up involve?
- How can I stay well after my treatment has finished?
- What symptoms of relapse or late effects should I look out for?
- Where can I go for help, support and advice between appointments?

What are follow-up appointments for?

Follow-up is a two-way process. It allows your medical team to check on your progress and it gives you an opportunity to ask any questions or raise any concerns you have about lymphoma and its treatment, including your **finances, return to work, immunisations** and **travel**.

Monitoring your recovery

Follow-up appointments aim to monitor your **recovery after treatment**. You can discuss any ongoing **side effects** of treatment with your medical team, and how best to manage them. You'll be asked about your general health and about your physical and **emotional wellbeing**. As well as carrying out medical checks, your medical team will support you in preparing for the future and living well after your treatment. They can also help you access any emotional or psychological support you need.

Checking for signs of relapse

Follow-up appointments allow your medical team to check for any signs or **symptoms** that might suggest your lymphoma has **relapsed** (come back). Although it can be upsetting thinking about potential relapse, talking to your team about it can help you understand what to look for and how to recognise if treatment may be necessary.

If you think your lymphoma might have relapsed, contact your medical team straight away. They may be able to reassure you or, if necessary, they might arrange further tests.

Managing late effects of treatment

Late effects are health problems that can affect you months or even years after you have stopped having treatment. They might be long-term side effects of your treatment or they could be new problems caused by your treatment that develop months or years after finishing treatment.

Follow-up appointments give you an opportunity to discuss how late effects are affecting you or could affect you in the future. Your medical team can refer you to other professionals as appropriate. For example, if your **fertility** is reduced or you have **peripheral neuropathy** (nerve damage), you could be referred for specialist help and advice. Your medical team will work with your GP to monitor any late effects in the long-term.

Before follow-up appointments

Some people feel anxious in the time leading up to follow-up appointments. It can help to prepare yourself mentally. Talk through your concerns with a friend or family member to help you process your thoughts and to lower your anxiety levels.

Remember that if you have no new **symptoms**, it is unlikely that your lymphoma has returned. You could keep a symptom diary, such as the **Macmillan organiser**, to help track whether any problems are getting better or worse.

Before your appointment, pay attention to your thoughts and feelings. Write down any concerns or questions you'd like to discuss with your medical team. Remember that appointments are a two-way process and give you an opportunity for a collaborative discussion with your medical team.

There is a lot of information to take in during end-of-treatment meetings and follow-up appointments. You might want to take someone with you to help you remember all your questions and the information your medical team gives you. Don't be afraid to take notes or ask to record conversations with your consultant or nurse specialist and listen to them later.

What happens at follow-up appointments?

At a follow-up appointment, you might see your consultant, clinical nurse specialist, or another member of your medical team.

Discussion

Your medical team talks to you about how you're feeling and whether you've noticed any change in your symptoms or any new symptoms. They also ask how you are adjusting to life after treatment, especially how you are coping emotionally and whether you feel able to return to the things you used to do before treatment. They can help you access any further support that could be helpful to you.

Physical examination

Your nurse or doctor might:

- take your temperature, pulse and blood pressure
- weigh you
- listen to your heart and lungs
- feel your abdomen (stomach), armpits, groin and neck to check for **enlarged lymph nodes** or an enlarged liver or **spleen**
- examine any other areas of your body that were previously affected by lymphoma.

Blood tests

Blood tests can help give your medical team a picture of your overall health. You might not need a blood test. Your medical team will tell you if you do and why. Changes in your blood do not necessarily have anything to do with your lymphoma. Many happen as a normal response to infection or injury. Some changes could prompt your medical team to carry out further tests.

Routine blood tests might include:

- a **full blood count**
- liver and kidney function tests
- tests to measure markers of inflammation, such as lactate dehydrogenase (LDH), C-reactive protein (CRP) or erythrocyte sedimentation rate (ESR)
- tests to check for abnormal proteins in your blood.

Blood tests can also help detect **late effects** of lymphoma treatment. For example, if you had **radiotherapy** to your neck, you will have tests once a year to check how well your thyroid gland is working. If you are at an increased risk of developing heart disease because of your lymphoma treatment, your GP might check your cholesterol levels and blood pressure each year even after your follow-up period is over.

Scans

After you finish treatment, you may have a **scan** to help your doctors assess how well your lymphoma has responded. In most hospitals, scans are not done routinely after this point. Doctors may order a scan if they suspect that your lymphoma could be relapsing.

When will my follow-up finish?

The length of your follow-up depends on several factors, including:

- your lymphoma type
- the usual practice at your hospital
- your individual situation
- how long it's been since you've finished your treatment
- **whether you have been treated as part of a clinical trial.**

Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

Most hospitals offer follow-up appointments – pre-booked or patient-triggered – for at least 2 years after you finish treatment. This is an important time in terms of your recovery from treatment and the risk of relapse. Some hospitals offer follow-up for 5 years or longer.

After your follow-up period ends, your GP usually becomes your main point of contact if you have any concerns or notice anything unusual. Your GP will have a record of your diagnosis and all the treatment you've had.

Low-grade non-Hodgkin lymphoma

If you've had low-grade **non-Hodgkin lymphoma** (sometimes called 'indolent' lymphoma), you are likely to be followed-up for the rest of your life. This might be through regular, pre-booked appointments or through a **remote monitoring** scheme where you arrange your own follow-up appointments as-and-when you feel you need one. Your GP or medical team will still monitor your test results.

Follow-up on maintenance rituximab

If you are having maintenance **rituximab**, you will be followed up regularly during the maintenance period. You will be seen less frequently afterwards. Your doctor will advise you on how often this should be.

Follow-up when you are treated as part of a clinical trial

If you have been treated as part of a **clinical trial**, you will be followed up according to the trial protocol (which outlines how the trial should run). Clinical trials often monitor long-term health, so follow-up may go on longer for people who are participating in a clinical trial than for those who aren't.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

Acknowledgements

- With thanks to Gilly Howard-Jones, Lymphoma Clinical Nurse Specialist and Macmillan recovery package lead at University Hospital Southampton, for reviewing this information.
- We would like to thank the members of our Reader Panel who gave their time to review this information.

Content last reviewed: October 2018

Next planned review: October 2021

LYMweb0067FollowUp2018v3



© Lymphoma Action

Tell us what you think and help us to improve our resources for people affected by lymphoma. If you have any feedback, please visit www.lymphoma-action.org.uk/Feedback or email publications@lymphoma-action.org.uk.

All our information is available free of charge. If you have found it useful and would like to make a donation to support our work you can do so on our website www.lymphoma-action.org.uk/Donate. Our information could not be produced without support from people like you. Thank you.

Disclaimer

We make every effort to make sure that the information we provide is accurate at time of publication, but medical research is constantly changing. Our information is not a substitute for individual medical advice from a trained clinician. If you are concerned about your health, consult your doctor.

Lymphoma Action cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information we refer to, including that on third party websites.

Neither the Information Standard scheme operator nor the scheme owner shall have any responsibility whatsoever for costs, losses or direct or indirect damages or costs arising from inaccuracy of information or omissions in the information published on the website on behalf of Lymphoma Action.