

## Follow-up for lymphoma

This information is about follow-up appointments you have after treatment for lymphoma: their aims, what they might involve and how to prepare for them. It is relevant to all age groups, although children, teenagers and young adults might have additional checks on growth and development.

We have separate information about **self-management and remote monitoring**, **active monitoring ('watch and wait')** and **recovery after treatment**.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk).

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## What is follow-up?

After finishing **treatment for lymphoma**, you have an end-of-treatment appointment with your medical team. Your clinical nurse specialist or another health professional talks to you about how you feel. They might use a questionnaire to help guide this conversation – this is sometimes called a **holistic needs assessment** (HNA). During this discussion, you can ask any **questions you might have about your lymphoma**, as well as about any aspects of your personal life, including **day-to-day living**, **work**, **finances**, **vaccinations** and **travel**.

Together, you come up with a care and support plan specific to your individual needs, known as **personalised care and support**. This can include needs that are physical, emotional, social or financial. There might also be a health and wellbeing event of interest to you to support your recovery, such as our **Live your Life workshop**.

## Treatment summary

After treatment, your medical team should give you and your GP a written treatment summary outlining:

- your **treatment** and its possible **side effects**, including any that could be long-term
- any **late effects** you might get (side effects that appear months or years after your treatment finishes)
- symptoms to look out for that could show your **lymphoma has returned** (relapsed) and who to contact (at any time of the day or night) if you notice any
- any lifestyle recommendations, for example, about **diet** and **exercise**.

If you haven't been given one, ask a member of your medical team for a treatment summary.

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## How often will I have follow-up appointments?

Your follow-up care is planned for you as an individual. As a rough guide, one or more members of your medical team will see you every few months when your treatment first ends. After this, appointments usually become less frequent.

How often you have follow-up appointments depends on:

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

Some hospitals offer a **self-management and remote monitoring** system. Instead of having pre-booked appointments, you are supported to arrange your own follow-up and you book an appointment when you feel you need to.

Whether you have your follow-up by pre-booked or self-managed appointments, you can still contact a member of your medical team whenever you need to.

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# What are follow-up appointments for?

Follow-up appointments are important for both you and your medical team. During your appointments your medical team can **check your health and recovery** and talk to you about managing any **late effects of treatment**.

## Checking your health and recovery

Follow-up appointments monitor your **recovery after treatment**.

Your medical team will also ask you about your general health and **emotional wellbeing**, as well as about any side effects you might be experiencing. They can offer advice about how to manage these and support you to **live well, with and beyond lymphoma**.

Your medical team can also check for any signs that your lymphoma might be coming back (**relapse**). Although it can be upsetting to think about the possibility of relapse, talking to your team about it can help you to understand what to look for, in case you need further treatment.

**If you think your lymphoma might have relapsed, contact your medical team straight away. If necessary, they can arrange for you to have tests.**

## Managing late effects of treatment

**Late effects** are health problems that can affect you months or years after you have finished treatment. Late effects might be:

- long-term side effects of your treatment
- new problems caused by your treatment that develop months or years after finishing treatment.

Follow-up appointments give you an opportunity to talk to your medical team about how late effects are affecting you or could affect you in the future. Your medical team can then help you to find ways of managing them. In the longer-term, your medical team will work with your GP to monitor any late effects of treatment.

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## Before follow-up appointments

Your medical team will give you information about how often you'll be followed-up, where, when and the purpose of the appointment.

There can be a lot of information during a consultation. To help you get the most out of your appointment, you could:

- ask a family member or friend to go with you if the hospital allows this – as well as offering emotional support, they could help with remembering all that **you'd like to ask** and the information you're given
- take notes of the key points during the appointment.



**I found it useful to have a book to record questions in as they arose. This was especially useful when time between appointments extended to six months or longer so as not to forget my concerns.**

**Just before my appointment, I would review my list and some of my questions had already been answered in the intervening period.**

**Gill, followed-up after treatment for follicular lymphoma**

## **If you feel anxious before an appointment**

Some people feel anxious in the lead-up to a follow-up appointment. Think about what you'd like to get out of the appointment, for example, answers to any questions you have, guidance about **physical activity and exercise**, or where you can get **emotional support**. This can help to give you a sense of control and help you to feel more mentally prepared for the appointment.

You might also find it helps to process your thoughts by talking through your feelings with someone – for example, a close family member, a friend, or our [helpline services team](#).

It might reassure you to keep in mind that if you don't have any new [symptoms](#), it's unlikely that your lymphoma has returned. You could keep a symptom diary to help monitor any symptoms you have, how often you have them, how they affect you, and whether they improve or worsen. [Macmillan Cancer Support has an organiser](#) that can help with this.

We have some [tips about coping with waiting for test results](#). You might also find them helpful in reducing anxiety in the lead up to medical appointments.

**Much of the anxiety I felt throughout and beyond treatment was because I just didn't know what was going to happen next. This did reduce as time went on and I became familiar with follow up appointments.**

*Gill, followed-up after treatment for follicular lymphoma*

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## What happens at follow-up appointments?

You have your follow-up appointments with a member of your medical team, often your consultant or your clinical nurse specialist. After some time, your care might be transferred to your GP or practice nurse.

Follow-up appointments can happen in person or over the phone. Some hospitals might also give the option of having a video call. Speak to your hospital to find out what's available to you and to discuss your preferences, if you have any.

At your follow-up appointment, you and your doctor or nurse have a [discussion](#) about your physical health and emotional wellbeing. Follow-up might also involve a [physical examination](#) and [blood tests](#).

You might have a [scan](#) at the end of your treatment to check how well your lymphoma has responded. They are not routinely used as part of ongoing follow-up as there is no evidence to suggest that follow-up scans change lymphoma treatment or outcomes. Having scans only when they are considered to be helpful and safe helps to keep your exposure to radiation as low as possible.

## Discussion

Follow-up appointments are a chance for you to talk about:

- how you're feeling, physically and **emotionally**
- whether you've noticed any changes in your symptoms or any new symptoms
- how you're **adjusting to life after treatment**, for example, whether you've been able to return to the activities you used to do before treatment
- any further support that might be of interest to you, including how to access it. This might include **support groups** or a referral to a **dietician** or **physiotherapist**.

I met with my consultant every six months for follow-up appointments. I was incredibly lucky to have such a brilliant doctor assigned to my case. He was like a navigator for a giant container ship, slowly navigating me through the ups and downs of cancer treatment and care.

**Richard, diagnosed with non-Hodgkin lymphoma**

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## Physical examination

During your appointments, your doctor or nurse might feel:

- your stomach (abdomen), armpit, groin and neck for **swollen (enlarged) lymph nodes** or an enlarged liver or spleen
- any areas of your body that were affected by lymphoma, to check for any signs of **recurrence** or **late effects**.

## Blood tests

Sometimes, doctors use **blood tests** to check overall physical health. Changes in your blood can happen as a normal response to **infection** or injury – they might not be linked to your lymphoma or any cause for concern. Depending on the results of your blood tests, your medical team might carry out further **tests or a scan**.

Some blood tests can also help to detect **late effects** of lymphoma treatment. However, they're not often useful in checking for **relapse**. If you need a blood test, your medical team can tell you what they're checking for and why.

Blood tests that you might have as part of your follow-up include:

- a **full blood count**, which measures how many blood cells you have in your blood
- tests to check how well your liver and kidneys are working.

If you have had **radiotherapy** to your neck, you will have a blood test once a year to check how well your thyroid gland is working. Your thyroid gland is important for healthy metabolism, growth, development and controlling body temperature.

Some people have a higher risk of developing **heart disease** because of their lymphoma treatment. If this is the case for you, your GP might check your cholesterol levels and blood pressure each year even after your follow-up period is over.

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## How long does follow-up go on for?

As well as the usual practice at your hospital, the length of your follow-up depends on several factors, including:

- your **lymphoma type**
- the **type of treatment** you've had, including whether you were **treated as part of a clinical trial**
- how long it's been since you finished your treatment.

## Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

Most hospitals invite you to have follow-up appointments for around 2 years after finishing treatment for **Hodgkin lymphoma** and **high-grade non-Hodgkin lymphoma**, though some offer it for longer.

You usually have check-ups every few months at first, then every 6 months. Having frequent appointments during this time means that your medical team can check for any signs of your lymphoma coming back (**relapse**) – the risk of which is higher in the first 2 years after treatment.

After your follow-up ends, your GP usually becomes your main point of contact if you have any concerns or notice new symptoms. Many hospitals also offer a phone number to call if you have any concerns about relapse.

## Low-grade non-Hodgkin lymphoma

With **low grade non-Hodgkin lymphoma** (sometimes known as 'indolent' lymphoma), you're likely to have follow-up appointments for the rest of your life. This is because most low-grade non-Hodgkin lymphomas are long-lasting, flaring up from time to time but otherwise needing no treatment. You might go for years at a time without needing treatment.

Your follow-up might be through pre-booked appointments or through a **self-management scheme**. Either way, your medical team should provide ongoing support. They will monitor your test results and discuss any issues with you.

### Follow-up on maintenance therapy

If you have maintenance therapy (for example, **rituximab**), you will have follow-up appointments:

- regularly, in person, during your maintenance period (your medical team will tell you how long this is likely to be) – this is to check your fitness and response to treatment
- less frequently after this time, until you return to routine follow-up.

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

**Clinical trials** each have their own trial protocol. The protocol outlines how the trial should run, including the schedule of follow-up care. Often, researchers want to find out about the long-term health of participants of a clinical trial so follow-up goes on for longer than it does for other treatments.

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## References

The full list of references for this page is available on our website. Alternatively, email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619409 if you would like a copy.

## Acknowledgements

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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