

# Follow-up after lymphoma treatment

Follow-up after treatment is to help support your long-term health and recovery. This information is about what follow-up might involve. 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?

Your medical team should continue to offer [personalised care and support](#) after you finish [lymphoma treatment](#). Follow-up is part of this and is designed to help check your health and recovery.

### End of treatment appointment

After finishing [treatment for lymphoma](#), you will have an end-of-treatment appointment with your medical team. During this, 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, sometimes called a [holistic needs assessment](#) (HNA). HNAs should form part of your care from the point of diagnosis onwards. 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 plan care and support that suits your individual needs ([personalised care and support](#)). This can include needs that are physical, emotional, social or financial. There might also be health and wellbeing events of interest to you to support your recovery, such as our [Live your Life workshop](#).

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## Treatment summary

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

- the [treatment](#) you've had, 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)
- possible signs or symptoms that could show your [lymphoma has returned](#) (relapsed), as well as 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 would like further information about your treatment summary and any possible late effects, talk to your medical team.

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As part of the end of treatment summary, we offer guidance to GPs of how to manage care after treatment for lymphoma. This includes information on vaccinations, checking heart function longer-term, and checks for things such as cholesterol, blood pressure and diabetes.

Chrissie Kirby, Haematology Clinical Nurse Specialist

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## What is the schedule for follow-up appointments?

Follow-up care is personalised, which means it is planned for you as an individual.

As a rough guide, you'll have an appointment with one or more members of your medical team 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 were diagnosed with
- **treatment** you've had
- policies and practices in your hospital or treatment centre.

Your medical team will give you information about how often you'll be followed-up, where, when and the purpose of the appointment. They can also tell you about **how long your follow-up is likely to go on for**.

Some hospitals offer a **self-management and remote monitoring** system. Instead of having pre-booked appointments, you are supported to arrange an appointment if you have concerns or symptoms. This is often known as 'patient-led follow-up'.

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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## Before follow-up appointments

There can be a lot of information during a consultation. To help you get the most out of your appointment, you could take notes of the key points of the appointment. You might also want to take someone with you, such as a family member or friend – as well as offering emotional support, they could help with remembering all that you'd like to ask and the information you're given.

### 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 talk through your feelings with someone – for example, a close family member, a friend, or our [Helpline Team](#).

It might reassure you to keep in mind that if you don't have any new or returning [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.

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## What happens at follow-up appointments?

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

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.

After some time, your care might be transferred to your GP or practice nurse.

You might have a **scan** at the end of your treatment to check how well your lymphoma has responded. Scans are not routinely used as part of ongoing follow-up as they are unlikely to identify lymphoma. There is also no evidence to suggest that they change lymphoma treatment or outcomes. Your medical team will request scans if they have concerns about your symptoms.

## Follow-up 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
- **your adjustment 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**.

## Physical examination

During your follow-up 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 the lymphoma coming back (**relapsing**) or **late effects**.

## Blood tests

Some people will need to have **blood tests** at follow-up. However, for many people, they are not necessary. Blood tests are sometimes done for certain subtypes of lymphoma or if you have specific symptoms.

If you need a blood test, your medical team can tell you what they're checking for and why.

Some blood tests can also help to detect **late effects** of lymphoma treatment, for example checking thyroid function after radiotherapy to the thyroid gland.

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

- **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.

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## How can follow-up help me?

Follow-up means that your medical team can **check your health and recovery** from treatment. It also gives them a chance to support you with any ongoing side effects you might experience and to talk to you about managing any **late effects of treatment**.

### Checking your health and recovery

Follow-up appointments monitor your **recovery after treatment**. This includes addressing any practical, financial, physical, emotional and social needs you might have (holistic needs).

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.

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.

Follow-up appointments give you an opportunity to talk to your medical team about any late effects – this might be any you're experiencing now, or those you might 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 you and your GP to monitor any late effects of treatment.

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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:

- the **lymphoma type** you were diagnosed with
- 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

Many 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.

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

Most **low grade non-Hodgkin lymphomas** (sometimes known as 'indolent' lymphomas) are long-lasting. They can flare up from time to time but otherwise

need no treatment. For this reason, you're likely to have follow-up appointments for the rest of your life.

Your follow-up might be through pre-booked appointments or through a [self-management scheme](#), where you arrange appointments when you need to. 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.

During your maintenance period, you'll have regular, in-person appointments. These are to check your health and fitness, as well as your response to treatment.

Your medical team will tell you how long your maintenance period will be.

After this time, your appointments will become less frequent, until you return to routine follow-up.

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

Each [clinical trial](#) has its own protocol. The protocol outlines how the trial should run, including the schedule of follow-up. 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.

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