What happens if lymphoma relapses?

This page provides an overview of what might happen if lymphoma comes back (relapses) or doesn’t respond to treatment (refractory lymphoma).

On this page

What is relapsed or refractory lymphoma?
Who might experience relapse?
How will I know if my lymphoma has relapsed?
What happens if lymphoma relapses?
How is relapsed or refractory lymphoma treated?
What happens if there is no further treatment for my lymphoma?

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.

What is relapsed or refractory lymphoma?

**Relapsed lymphoma** is lymphoma that comes back after successful treatment and a period of **remission** (no evidence of lymphoma on tests and scans).

**Refractory lymphoma** is lymphoma that does not respond well to the first choice of treatment.

Having refractory lymphoma or experiencing a relapse can be very distressing, but many people are successfully treated again and go into remission. In general, the same treatment options are used for relapsed lymphoma and refractory lymphoma.
Who might experience relapse?

Relapse can occur if there are lymphoma cells left in your body after treatment. These cells can gradually build up and begin to cause problems again.

This might be the case if you had a **partial remission** (your lymphoma got smaller during treatment but it did not go away completely). It is also possible for some people who had a **complete remission** (no evidence of lymphoma on your tests and scans after treatment) to experience a relapse. This is because there might be a small number of lymphoma cells left that can’t be detected by standard tests.

Some types of lymphoma are more likely to relapse than others.

**Hodgkin lymphoma and high-grade non-Hodgkin lymphoma**

Most people with **Hodgkin lymphoma** and **high-grade non-Hodgkin lymphoma** who go into remission do not experience relapse. However, some types of high-grade non-Hodgkin lymphoma are likely to relapse. These include:

- **mantle cell lymphoma**
- **many types of T-cell lymphoma**.

A small proportion of people with Hodgkin lymphoma or with other types of high-grade non-Hodgkin lymphoma might also relapse.

Most relapses of Hodgkin lymphoma or high-grade non-Hodgkin lymphoma happen within the first 2 years after treatment. As time goes on, relapse generally becomes less likely.

**Low-grade non-Hodgkin lymphoma**

**Low-grade non-Hodgkin lymphoma** grows slowly. Lymphoma treatments are usually most effective at killing fast-growing cells. Some of the slow-growing cells in low-grade lymphoma might ‘escape’ treatment and stay in your body. For this reason, it is common for low-grade non-Hodgkin lymphoma to relapse and need more treatment.

If you have low-grade non-Hodgkin lymphoma that isn’t causing troublesome symptoms, it is not unusual to be on **active monitoring (‘watch and wait’)** until you need treatment, or in between courses of treatment.
As treatment options for low-grade non-Hodgkin lymphoma improve, remissions are lasting longer. Relapse might not happen for many months or years. You might have long periods when you feel well. You might have other times when you need treatment. It helps some people to think of low-grade non-Hodgkin lymphoma as a long-term (chronic) condition that needs treatment from time-to-time.

Sometimes low-grade non-Hodgkin lymphoma can change (transform) into a faster-growing lymphoma as it relapses. We have separate information on transformed lymphoma.

How will I know if my lymphoma has relapsed?

It is natural to feel worried about your lymphoma relapsing after you’ve finished treatment. Whenever you feel ill, you might worry it’s the lymphoma again. However, you’re as likely as anybody else to get coughs, colds and other illnesses, which might be completely unrelated to lymphoma. Lots of things can cause lymph nodes to swell.

It can be difficult to get the right balance between monitoring your health and worrying unnecessarily over minor symptoms. It’s a good idea to be aware of the signs of relapse to look out for.

If lymphoma relapses, it’s usually noticed first by the person with lymphoma, not by their doctor or nurse. It might come back where it was before or it might affect a different part of your body. You might have the same symptoms as before or different symptoms. You might notice new, or bigger, lumps. You might get more general symptoms, such as fevers, night sweats, weight loss or itching. The signs of relapse also depend on what type of lymphoma you had. Your medical team should tell you what to look out for when you finish your treatment. Ask them if you’re not sure.

Contact your medical team if you have any of the following symptoms:

- **enlarged lymph nodes** lasting more than a week
- **drenching night sweats** lasting more than a few weeks
- **unexplained weight loss**
- **worsening fatigue**
- **itching**
- **a rash** (if you have skin lymphoma)
- **diarrhoea**
- persistent or unexplained **pain**.
Make sure you attend all your follow-up appointments. **If you think your lymphoma might have relapsed, contact your medical team straightaway. You don't have to wait for your next appointment.** They might be able to reassure you or, if necessary, they might arrange further tests.

### What happens if lymphoma relapses?

If your medical team thinks your lymphoma might have relapsed, you are likely to have tests, including **blood tests** and **scans**. You might also have another **biopsy**.

The information your medical team gets from these tests helps them work out the best treatment for you. There are several treatment options for lymphoma that has relapsed.

### Your feelings after relapse

It can be very distressing to have a relapse of lymphoma. Even if you expect your lymphoma to relapse, it can still be upsetting when it happens.

Each person reacts differently to relapse. For many people, experiencing a relapse brings back a whole **range of emotions** they felt when they were first diagnosed. These emotions might be no easier to cope with the second time around, even if you are aware that there are good lymphoma treatments available. Some people feel frightened about having more treatment, particularly if they found treatment hard the first time.

Let your medical team or key worker know how you feel. They are best-placed to give you information based on your individual circumstances. You might find it helpful to have a friend or relative with you when you talk to your medical team. Make a list of any questions you have and take it to your appointment with you so you remember to ask them all. Learning about your lymphoma and your treatment options can help you to feel more prepared and in control.

Talking about how you feel might help you process your thoughts. If you feel anxious, talking about it might help lower your anxiety or **stress** levels. You might want to speak to a friend or relative. For some people, though, having these conversations with the people closest to them is difficult. If this is the case for you, you might find it helpful to talk to your key worker or get in touch with our **Helpline Services**.
If your feelings continue for a significant period of time and are affecting your day-to-day life, you might find counselling helpful. A counsellor is trained to offer support in coping with challenging feelings. If you are interested in counselling, ask your GP, hospital doctor or clinical nurse specialist if they can refer you. Alternatively, you can search for a private, registered counsellor using the British Association for Counselling and Psychotherapy’s (BACP) online search tool.

How is relapsed or refractory lymphoma treated?

The treatment options for relapsed or refractory lymphoma depend on several factors, including:

- the type of lymphoma you have
- your symptoms and your test results
- what treatment you had previously and how well your lymphoma responded to it
- what clinical trials are available for your type of lymphoma
- how you coped with any treatment you had previously
- how long it has been since you were treated
- any other medical conditions you have
- your general fitness.

We give some information below about the most likely treatment options for relapsed or refractory Hodgkin lymphoma, high-grade non-Hodgkin lymphoma and low-grade non-Hodgkin lymphoma. Our pages on different types of lymphoma give more specific information on relapse for each type.

Relapsed or refractory Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

Most people with relapsed or refractory Hodgkin lymphoma and high-grade non-Hodgkin lymphoma have more treatment. Below we outline the main treatment options. Our pages on different types of lymphoma give more specific information on how relapse is treated for each type.

If you have relapsed or refractory Hodgkin lymphoma or high-grade non-Hodgkin lymphoma, you are likely to be offered a more intensive treatment than your first treatment in order to achieve a remission.
• Often a different type of **chemotherapy** is offered. This is likely to be stronger than the chemotherapy you had before. It might contain chemotherapy agents that you have not had before. It is sometimes called 'salvage therapy', 'second-line therapy' or 'rescue therapy'.

• If you are fit enough and you respond to salvage chemotherapy, your medical team might recommend that you have a **stem cell transplant using your own stem cells** (an ‘autologous’ stem cell transplant) to make your remission last as long as possible.

• **Targeted drugs** and **antibody therapies** (also known as ‘immunotherapy’) are available for some types of relapsed and refractory Hodgkin lymphoma or high-grade non-Hodgkin lymphoma.

• Other treatments might be available through a **clinical trial**. If you are interested in taking part in a clinical trial, ask your medical team if there is one that might be suitable for you, or search our database at **Lymphoma TrialsLink**.

Heather was diagnosed with **mantle cell lymphoma** in 2007 at the age of 59. She received **chemotherapy** with R-CHOP and R-DHAP and recovered well over the following 6 months. Her lymphoma returned twice in the next 5 years. She had FCR chemotherapy followed by **radioimmunotherapy** on her first relapse and **lenalidomide** on her second relapse. She started a 2-year course of **rituximab maintenance** in 2016 at the advice of her clinician and has now been in remission for 7 years.

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**I feel enormously lucky to be alive at a time when so many new drugs are coming into use. I have benefitted so much from this research.**

Heather, diagnosed with mantle cell lymphoma
What happens if I relapse again?

Some people with Hodgkin lymphoma or high-grade non-Hodgkin lymphoma experience more than one relapse. Treatment options for lymphoma that’s relapsed more than once might include:

- a different chemotherapy regimen
- a stem cell transplant using donor stem cells (an ‘allogeneic’ stem cell transplant)
- radiotherapy, if the lymphoma is only affecting one part of your body
- targeted drugs, which are available on the NHS for some types of relapsed and refractory lymphoma, or through clinical trials for other types
- CAR T-cell therapy, which is available on the NHS for diffuse large B-cell lymphoma (DLBCL) or primary mediastinal large B-cell lymphoma (PMBL) that has relapsed more than once.

More treatment options are becoming available for relapsed lymphoma all the time. Our pages on different types of lymphoma give more specific information on how each type is treated if it has relapsed more than once.

Stuart was diagnosed with Hodgkin lymphoma in 2015. He was initially treated with 6 months of chemotherapy but his lymphoma relapsed quickly so he had further treatment with surgery and radiotherapy. Stuart went back to work in September 2016 but by October, the lymphoma had relapsed again. He had an autologous stem cell transplant and has now been in remission for over 2 years.
Because my lymphoma had come back so quickly, my medical team explained that a transplant now needed to be considered. So over the Christmas period of 2016 I was being given ICE chemotherapy as conditioning treatment for an autologous stem cell transplant, using my own stem cells.

Stuart, diagnosed with Hodgkin lymphoma

Relapsed or refractory low-grade non-Hodgkin lymphoma

There are many treatment options for relapsed or refractory low-grade non-Hodgkin lymphoma. Below we outline the main treatment options. Our pages on different types of lymphoma give more specific information on how relapse is treated for each type.

Your medical team might discuss a range of treatments with you. These might include:

- active monitoring (watch and wait) if your lymphoma is not causing troublesome symptoms or affecting major organs
- radiotherapy if your lymphoma is only affecting one part of your body
- chemotherapy – either the same as you had before or a different regimen – usually combined with antibody therapy and often with steroids
- antibody therapy on its own
- radioimmunotherapy – a radioactive particle joined to an antibody, which takes the radioactive particle directly to the lymphoma cells (although this is not currently available on the NHS)
- targeted drugs, which are available on the NHS for some types of relapsed and refractory lymphoma, or through clinical trials for other types.

If you have had a long remission before your relapse, or if your lymphoma is not widespread, you are more likely to have less intensive treatments when you relapse. If you relapsed very quickly or your medical team feel you are at high risk of relapsing again, you might be offered more intensive treatment, such as a stem cell transplant.

Other treatments might be available through clinical trials. If you are interested in taking part in a clinical trial, ask your medical team if there is one that might be suitable for you. You can also search our database at Lymphoma TrialsLink.
Linda was first diagnosed with follicular lymphoma in 2000 at the age of 46. She was treated with chemotherapy as part of a clinical trial and went into remission. She relapsed 10 years later, in 2011, and was offered a choice of treatments. She had oral chemotherapy with chlorambucil, which kept her lymphoma under control. She had radiotherapy in 2014.

I was offered a choice of four treatments in 2011 and decided to keep rituximab as an option for the future. I have carried on with my life, although at a slower pace, and treasure it. I do some dog training, swimming and walk as much as I can. Exercise is a vital part of feeling well.

What happens if I relapse again?

Many people with low-grade non-Hodgkin lymphoma relapse more than once. You are likely to receive a number of different treatments over the course of your lymphoma, which aim to keep it under control. If you have a partial remission (your lymphoma has got smaller but has not gone completely) but your lymphoma is not causing problems, you are likely to go on active monitoring. Most people with low-grade non-Hodgkin lymphoma only need treatment from time to time when their lymphoma gets worse and starts to cause troublesome symptoms.

The treatment options for low-grade non-Hodgkin lymphoma that has relapsed again are similar to those used for first relapse. If you relapse several times in a short space of time, your medical team might recommend a more intensive approach, such as a stem cell transplant.
Our pages on different types of lymphoma give more specific information on how each type is treated if it has relapsed more than once.

Trevor was diagnosed with follicular lymphoma in 2012 at the age of 42. Trevor has received several types of treatment including several courses of chemotherapy and chemo-immunotherapy, an autologous stem cell transplant using his own stem cells and in January 2016, an allogeneic (donor) stem cell transplant.

We still have to wait and see what happens in the future and whether the lymphoma comes back, but for now it feels like we’ve all walked across burning coals and are on the other side.

Sue, whose husband Trevor had follicular lymphoma

What happens if there is no further treatment for my lymphoma?

For most people, lymphoma is treatable. This is the case even if it comes back several times. The range of treatment options for lymphoma is improving all the time.

In some people, however, lymphoma keeps relapsing. The best treatment options might have been tried already. Together, you and your medical team decide whether to continue active treatment, taking into account how likely it is to work. You also consider the possibility of more severe side effects from stronger treatments, and whether you are well enough to cope with them.
You and your medical team might talk about your life expectancy. If you have a limited life expectancy without or indeed with treatment, you might want to consider what is important to you and your loved ones. It might be helpful to think about what symptoms and worries you have that could affect whether or not you decide to continue with active treatment. For some people, maintaining independence and quality of life might outweigh the prospect of further treatment to gain a few weeks or months of life.

Ending active treatment is a deeply emotional and personal decision. If you are no longer having active treatment for your lymphoma, your medical team should continue to offer you palliative and supportive care. Palliative care aims to control your symptoms and improve your quality of life. At the end of life, palliative care is given to make your final days as comfortable as possible.

If you, or someone close to you, are ending active treatment for lymphoma, you might find it helpful to get in touch with our Helpline Services. You might also find sources of support on our list of useful organisations.

References

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

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