

Lymphoma that comes back (relapses) or doesn't respond to treatment (refractory)

This information is about lymphoma that comes back (relapses) or doesn't respond to treatment (refractory lymphoma).

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Frequently asked questions about relapsed and refractory 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 do 'relapsed lymphoma' and 'refractory lymphoma' mean?

Doctors sometimes use the terms '**relapse**' and '**refractory**' to describe lymphoma.

Relapse

Usually, doctors say that lymphoma has relapsed if it returns after successful treatment. This means that you have had a **remission** (no evidence of lymphoma on **tests and scans**) that lasts for at least 6 months after **treatment**.

Relapse can happen if there are lymphoma cells left in your body after treatment. For example:

- If your lymphoma gets smaller during treatment but didn't go away completely (**partial remission**), the cells can build up again.
- If you had a **complete remission** (no evidence of lymphoma on your tests and scans after treatment), you might have a small number of lymphoma cells left but they could not be seen from test results.

Some types of lymphoma are more likely to relapse than others. In general, those that are more likely to relapse include: **low-grade non-Hodgkin lymphomas** and **some types of high-grade non-Hodgkin lymphomas**. Most types of classical Hodgkin lymphomas are less likely to relapse.

Refractory lymphoma

Doctors might say that your lymphoma is refractory if it comes back within 6 months of treatment. There are **treatment options for refractory lymphoma**.

If your lymphoma doesn't change much after treatment, or grows during treatment, doctors might say that it is 'progressive'. It is treated in the same way as refractory lymphoma.

Relapsed low-grade non-Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma is likely to relapse and need more treatment. This is because chemotherapy works well on cells in that are in the process of dividing, as is the case of high-grade (fast-growing) lymphomas.

With low-grade lymphoma, the cells are slower to divide. They are more likely to be in a resting phase of the cell cycle when chemotherapy is delivered. For this reason, chemotherapy is less likely to be effective. Over time, these cells are likely to re-grow. Our video explains more about **what chemotherapy is and how it works**.

Many people relapse with low-grade non-Hodgkin lymphoma that isn't causing troublesome symptoms. In these cases, doctors often recommend **active monitoring ('watch and wait')** until you need more treatment.

As treatment options for low-grade non-Hodgkin lymphoma become more and more effective, remissions last longer. Relapse might not happen for many years. It is not possible to predict when it will happen. Some people therefore think of low-grade non-Hodgkin lymphoma as a long-term (chronic) condition that needs treatment from time to time. There might be long periods of time when you feel well, and other times when you need treatment.

I felt a bit more relaxed about it all the second time around as relapse was more or less what I expected. I dropped off to sleep during the chemo infusions for my relapsed lymphoma. Even though I got a lung infection, I felt I dealt with that OK too.

Maureen, treated for relapsed follicular lymphoma

Sometimes, low-grade non-Hodgkin lymphoma can come back as a faster-growing lymphoma. This is known as **transformation of lymphoma**.

Relapsed Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

Most people with **Hodgkin lymphoma** or **high-grade non-Hodgkin lymphoma** who go into remission do not relapse.

However, some types of high-grade non-Hodgkin lymphoma are likely to relapse. These include:

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

Some 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.

How will I know if my lymphoma has relapsed?

The signs of relapse depend on what type of lymphoma you had. **Your medical team should tell you what to look out for when you finish your treatment. If you have any questions or would like further guidance, ask them.**

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

- **swollen lymph nodes** lasting more than a few weeks
- **drenching sweats** lasting more than a few weeks
- **unexplained weight loss**
- **worsening fatigue**
- **itching**
- a **rash**, if you have **skin lymphoma**
- **a change in bowel patterns**
- persistent or unexplained **pain**.

If your medical team think that relapse is possible, you are likely to have tests, including **blood tests** and **scans**. You are likely also to have another **biopsy**. This is to give doctors as much information as possible about the cause of your symptoms. If your lymphoma has come back, it might not be the same type or stage as the lymphoma you had before. Based on the results, your medical team plan the best **treatment for you**.

Treatment for relapsed or refractory lymphoma

Treatment for relapsed or refractory lymphoma depends on several factors, including:

- the **type of lymphoma** you have
- your **symptoms** and results of **tests and scans**
- what **treatment** you had before, and how well your lymphoma responded to it
- whether there are any **clinical trials** available for your type of lymphoma
- how you coped physically and **emotionally** with any previous treatment
- how long it has been since you were treated
- any other medical conditions you have
- your general health and fitness.

Some **clinical trials** test potential new treatments for different types of lymphoma, including lymphomas that have relapsed or are refractory.

Below, we outline some of the most likely treatment options for relapsed or refractory:

- **low-grade non-Hodgkin lymphoma**
- **Hodgkin lymphoma**
- **high-grade non-Hodgkin lymphoma.**

You'll find more detailed information on treatments, including those used in cases of relapse, in our separate information about different **types of lymphoma**.

Treatment for relapsed or refractory low-grade non-Hodgkin lymphoma

Your treatment plan is tailored to your individual circumstances.

If your remission lasted a long time and the relapsed lymphoma is not widespread, you might have less intensive treatment than the first time around.

If your relapse happened quite soon after treatment, your medical team will decide on the best treatment options. If they think you're at high risk of relapsing again, they might offer more intensive treatments, such as a such as a **stem cell transplant**.

In general, treatments for relapsed or refractory low-grade non-Hodgkin lymphoma might include:

- **active monitoring** ('watch and wait') if your lymphoma is not causing troublesome symptoms or affecting major organs or structures
- **radiotherapy** if your lymphoma is only affecting one group of lymph nodes
- **chemotherapy**, either with the same chemotherapy drugs you had before, or using a different drug combination (regimen). Usually, these are given together with **antibody therapy**, and often with **steroids**
- **antibody therapy** or immunotherapy
- **targeted drugs** that are available on the NHS for some types of relapsed and refractory lymphoma. For other types, you might be able to access these drugs through a **clinical trial**
- **radioimmunotherapy**, a combination of radiation therapy and immunotherapy – however, this is not currently available on the NHS
- treatments to help with symptoms and side effects (**supportive treatments**).

After 12 years in remission, I had my 6-monthly check-up with my lymphoma oncologist and nothing was showing in my bloods, although the lump was slowly growing. I was sent for a skull X-ray, ultrasound scan, MRI scan and finally a biopsy. The biopsy showed that my follicular lymphoma had relapsed. I was given a choice of 4 treatments. I chose to take a course of chlorambucil, a form of oral chemotherapy. I took 2 tablets every day for 6 months and my side effects were almost non-existent. The tumour didn't go completely but was classed as 'stable disease'. The lymphoma started to regrow again a couple of years later and I had radiotherapy. 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.

Linda, treated for relapsed follicular lymphoma

What happens if I relapse again after treatment for relapsed low-grade non-Hodgkin lymphoma?

Low-grade non-Hodgkin lymphoma often relapses more than once. You are likely to need a number of different treatments over the course of your lifetime, to keep the lymphoma under control.

Most people with low-grade non-Hodgkin lymphoma only need treatment from time to time when their lymphoma starts to cause troublesome symptoms.

Some people have a **partial remission**, where the lymphoma gets smaller after treatment but has not gone completely. If this happens but your lymphoma is **not** causing problems, you are likely to go on **active monitoring**.

The treatment options for low-grade non-Hodgkin lymphoma that has relapsed again are similar to those used for first relapse.

If you relapse quickly, your medical team might recommend a more intensive approach, such as a **stem cell transplant**. We have separate information about **different types of lymphoma**, which give more specific information on how each type is treated if it has relapsed more than once.

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.

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. The aim of this is to achieve a remission. The treatment you are offered might include:

- A different type of **chemotherapy**. This is likely to be stronger than the chemotherapy you had before. It might also contain chemotherapy drugs that you have not had before. It is sometimes called 'second-line therapy' or 'third-line therapy'.
- A **stem cell transplant** using your own stem cells (**autologous stem cell transplant**) if you are fit enough and your lymphoma responds to the more intensive chemotherapy. Your medical team might recommend this to achieve a remission that lasts as long as possible.
- **Targeted drugs and antibody therapies** (also known as 'immunotherapy') for some types of relapsed and refractory Hodgkin lymphoma or high-grade non-Hodgkin lymphoma.
- Treatment through a **clinical trial**, if there is one that's suitable for you.

It is always worth discussing treatment options with your consultant or Clinical Nurse Specialist. I found my relapses very distressing especially after the long period of remission after my autologous stem cell transplant.
Nuala, treated for relapsed DLBCL

What happens if I relapse again after treatment for Hodgkin lymphoma or high-grade non-Hodgkin lymphoma?

Some people with Hodgkin lymphoma or high-grade non-Hodgkin lymphoma relapse more than once. If this happens, options for further treatment might include:

- **chemotherapy** with a different combination of drugs (**regimen**) to those you had before
- stem cell transplant using donor stem cells (**allogeneic stem cell transplant**)
- **radiotherapy**, if the lymphoma confined and can be safely reached with radiotherapy
- **targeted drugs** that are available on the NHS for some types of relapsed and refractory lymphoma. For other types, you might be able to access these drugs through a **clinical trial**.
- **CAR T-cell therapy**, which is available on the NHS for relapsed or refractory **diffuse large B-cell lymphoma** (DLBCL) or **primary mediastinal large B-cell lymphoma** (PMBL), and in some cases of **mantle cell lymphoma**.

I initially had six months of chemotherapy and it looked as though this had provided a remission from the lymphoma, but my lymphoma relapsed twice. Because it had come back so quickly, my medical team explained that a transplant now needed to be considered. Once I got out of hospital the first two months were a real struggle. However, I am delighted to now have two children. I also work in a supermarket. My employers have been excellent and understanding during my whole treatment and recovery.

Stuart, treated for relapsed Hodgkin lymphoma

Frequently asked questions about relapsed and refractory lymphoma

Below, we answer some of the questions people often have about relapsed and refractory lymphoma. Your medical team is best-placed to talk to you about your individual situation.

Why do I need another biopsy for relapsed lymphoma?

To help plan the best treatment for you, you are likely to have another biopsy and tests to help stage your lymphoma.

Will the relapsed lymphoma be the same as the lymphoma I had before?

If lymphoma comes back, it might be the same type as it was before and affect the same part of your body. You might have the same symptoms as before. However, the lymphoma might be in a different place, or at a different stage. It might cause different symptoms. Sometimes low-grade lymphoma might come back as high-grade lymphoma (transformation). In some cases, high-grade lymphoma comes back as low-grade lymphoma. This is why a further biopsy is done at relapse. It helps your medical team choose the most suitable treatment available for the best outcome. If you have a different **type of lymphoma** when it comes back, this is classed as a new diagnosis as opposed to relapse.

How can I cope with the uncertainty of a possible relapse?

It can be difficult to get a balance between monitoring your health and becoming very worried about minor symptoms. For example, **lymph nodes** can swell for lots of reasons, including in response to a common cold. Ask your medical team about any warning signs to look out for – most of the time, signs of possible relapse are first noticed by the person with lymphoma.

Give yourself time to adjust mentally to having been treated for lymphoma. It can be helpful to find ways to lower anxiety and **manage stress**. You might also be interested in our peer-led **Live your Life self-management programme**.

What emotional support is available if I relapse?

Relapse can bring a **range of emotions** – you might feel similar to when you were first diagnosed. Some people feel nervous about having more treatment. This might be the case if you found treatment very physically or emotionally challenging the first time around. Other people might feel more assured and confident – they feel more comfortable with the idea, having been through treatment once already.

Talk to your **key worker** or another member of your medical team about how you feel. They are best-placed to give you information based on your individual circumstances. Some people find it helpful to have a friend or family member with them when they have an appointment about their relapse. You could note **any questions you have** and take it to your appointment so that you remember to ask them all the things that are important to you. Learning about your lymphoma and your treatment options can help you to feel more prepared and in control.

You might also want be interested in:

- our **Helpline services**, which include a freephone helpline, **online support meetings** and a **peer support buddy service**
- a talking therapy, such as **counselling** – speak to a member of your medical team or your GP if you'd like to access counselling on the NHS. You can also search for a private therapist, for example, using the **Counselling Directory**, a nationwide database of qualified counsellors and psychotherapists.

Our useful organisations webpage includes a list of **sources of emotional support to enhance mental wellbeing**.

Is there anything I can do to help prevent a relapse?

There is nothing you have or haven't done to **cause your lymphoma** to relapse.

You can, however, help to put yourself in the best possible position to manage a relapse if it happens. Follow a **healthy lifestyle**, attend **follow-up appointments**, and contact your medical team straightaway if you think you might have relapsed. Be vigilant to any **warning signs of possible relapse** – ask your medical team what to look out for.

We also have **information and a video about checking your lymph nodes**. Ask your medical team how often to do so.

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

For most people, lymphoma is treatable, even if it comes back several times. The range of treatment options for lymphoma continues to improve over time.

In some people, however, lymphoma repeatedly relapses. Your medical team might already have tried the most appropriate treatment options for you.

Together, you and your medical team decide whether to continue active treatment, taking into account:

- how likely it is to work
- the possibility of more severe **side effects** from stronger treatments
- whether you are well enough to cope with them.

Whether to continue active treatment for lymphoma or not is a very personal decision. Some people choose quality of life over a longer life – it depends on what is important to you. Even if there is no further active treatment available, you should be offered treatment to help control your symptoms and improve your quality of life (**palliative care**).

It can be highly emotional if you or someone you love is considering whether to end active treatment. You might like to speak to a member of [our Helpline team](#) for emotional support during this time.

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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