

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

Lymphoma that doesn't respond to treatment is called refractory lymphoma. Lymphoma that comes back after successful treatment is called relapsed lymphoma.

There are treatment options available for both refractory and relapsed lymphoma.

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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.

What does 'refractory lymphoma' mean?

Your medical team 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, your medical team might say that it is 'progressive'. It is treated in the same way as refractory lymphoma.

I was given the news that first line treatment had failed. I try to hold things together when others are with me, but that news gave me a panic attack with the realisation of having to go through it all again – biopsies, scans and treatment. I felt so sick through the stress of it all.

Zoe, diagnosed with refractory primary mediastinal large B-cell lymphoma

Read [Zoe's story](#).

What does 'relapsed lymphoma' mean?

Your medical team might say that your 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.

You can listen to our **podcast**, in which Advanced Nurse Practitioner Charlotte Bloodworth talks about relapse and addresses some commonly asked questions.

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

Relapsed low-grade non-Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma is likely to relapse over time and need more treatment.

Chemotherapy works by killing cells that are in the process of dividing. The lymphoma cells divide slower in low-grade lymphoma compared to high-grade lymphoma. This means 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 at killing all of the lymphoma cells. Over time, the remaining cells are likely to grow and divide.

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

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.

Maureen, treated for relapsed follicular lymphoma

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

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 do have the possibility of relapsing.

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. This is why follow-up appointments tend to become less regular with time.

Just as my life resumed to normal again, I felt a pea-sized lump on my neck. Scans showed mediastinal lymphadenopathy, and they were almost certain the lymphoma had returned. I needed to have a biopsy so that they could confirm the type, which came back as Hodgkin lymphoma again, but this time stage 2. I was so angry, frustrated and devastated to be doing it all again. I had been told

that the chances of the lymphoma coming back were low, which left me questioning why this was happening to me again.

Faye, diagnosed with relapsed Hodgkin lymphoma

Read [Faye's story](#).

Treatment for relapsed or refractory lymphoma

For most people, relapsed or refractory lymphoma is treatable. Treatment is often referred to as 'second line treatment'.

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 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.

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

- [low-grade non-Hodgkin lymphoma](#)
- [Hodgkin lymphoma or high-grade non-Hodgkin lymphoma](#).

You'll find more detailed information on treatments, in our separate information pages about each of the different [types of lymphoma](#).

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

Your treatment plan is tailored to your individual circumstances.

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)
- **antibody therapy**
- **targeted drugs**
- treatments to help with symptoms and side effects (**supportive treatments**).

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. It is now 26 years since my diagnosis.

Linda, treated for relapsed follicular lymphoma

Read [Linda's story](#).

Treatment for relapsed or refractory Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

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 will depend on your type of lymphoma, your previous treatment and how you responded to it. It 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.
- A **bispecific antibody**. These stick to two different target proteins – one on lymphoma cells and one on healthy T cells (immune cells that can kill other cells), to help the T cells of your immune system to find and destroy the lymphoma cells.
- **CAR-T cell therapy**. This uses modified cells from your own immune system to fight lymphoma.
- Other **targeted therapies**. There are a variety of types – the specific treatments available to you will depend on your lymphoma type.
- 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.
- Treatment through a **clinical trial**, if there is one that's suitable for you.

My health began to deteriorate quite rapidly. I was short of breath and was struggling to walk due to pains in my legs. Another PET/CT scan revealed the lymphoma had become more widespread, and my consultant suspected that the lymphoma had transformed. This was confirmed by a bone marrow biopsy. I was referred to a specialist hospital to be considered for CAR-T cell therapy, which I went on to have. I felt very apprehensive, hoping the treatment was successful. But I am pleased to say that I have now been in remission for over three years.

Rachel, diagnosed with follicular lymphoma that transformed into diffuse large B-cell lymphoma

Read [Rachel's story](#).

Frequently asked questions about relapsed and refractory lymphoma

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 or GP 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 suspect a relapse, 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. Based on the results, your medical team plan the best **treatment for you**.

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 clinical nurse specialist 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.

You might be interested in our peer-led [Live your Life](#) programmes designed for people who have completed treatment or who are on active monitoring.

What happens if my lymphoma relapses again?

Low-grade non-Hodgkin lymphoma can relapse 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.

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.

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 is confined and can be safely reached with radiotherapy
- [targeted drugs](#)
- [CAR T-cell therapy](#).

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 increase and improve over time.

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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