Lymphoma in young people

This information is about lymphoma in people up to the age of 24. We have another page covering practical tips for young people with lymphoma.

If you are over 18, you may also find it useful to read our information on specific types of lymphoma in adults. Young people under the age of 18 may also find our information about lymphoma in children helpful, although this is aimed primarily at parents and carers.

On this page

What is lymphoma?
Symptoms
Tests, diagnosis and staging
Types of lymphoma in young people
Outlook
Treatment
Side effects and late effects of treatment
Relapsed and refractory lymphoma
After treatment

What is lymphoma?

Lymphoma is a type of cancer. It can develop when a type of white blood cell called a lymphocyte starts to grow in an abnormal, uncontrolled way.

Lymphomas are the most common group of cancers in teenagers and young adults. Around 1 in 5 young people diagnosed with cancer have lymphoma.

Figure: Around 1 in 5 young people diagnosed with cancer have lymphoma
Every year in the UK, around 500 young people aged 15 to 24 develop lymphoma.

In most cases, the cause of lymphoma is unknown. It is very unlikely that anything you have done has caused you to have lymphoma.

**Symptoms**

Lymphoma can be difficult for doctors to diagnose. Many of the symptoms (signs of illness) of lymphoma are also seen in other, less serious conditions.

People who have the same type of lymphoma can have different symptoms. Your symptoms will depend on where in your body the lymphoma is growing.

**Swollen lymph nodes**

The most common symptom that people notice is a lump or several lumps, usually in the neck, armpit or groin, that don’t go away after several weeks. These lumps are swollen lymph nodes (commonly called glands), where abnormal lymphocytes are growing.

You might have had swollen lymph nodes in the past when you had an infection, such as a sore throat. This kind of swelling is often painful but usually goes down within a couple of weeks. In lymphoma, lumps are usually painless and do not shrink back down to how they were before.

Many lymph nodes are deep inside your body and you can’t feel them from the outside. If the lymphoma starts in one of these lymph nodes, you might get other symptoms. If the lymphoma is growing in your chest, you might feel breathless or develop a cough. If it is growing in your abdomen (stomach), you might get abdominal pain.

There are other common symptoms of lymphoma. You might have some of these or no symptoms other than lumps. Everyone’s symptoms are different, and can include:

- **fatigue (extreme tiredness)**
- drenching sweats, especially at night, so that your night clothes or bedding are soaked through
- fevers (temperature above 38°C)
- weight loss when you are not trying to lose weight
- severe itching
- pain after drinking alcohol (this is rare but it might happen in an area of your body where Hodgkin lymphoma is growing).
Night sweats, unexplained weight loss and fevers often occur together. You might hear these three symptoms called 'B symptoms'. Having B symptoms can sometimes affect how you need to be treated.

**Tests, diagnosis and staging**

If your doctors think you might have lymphoma, you will need a lot of tests to confirm it. It is important that the doctors treating you find out what type of lymphoma you have and where it is in your body. This information is used to plan the best treatment for you.

**Having a biopsy: finding out what type of lymphoma you have**

You will need a small operation to remove the swollen lymph node or a part of it. This is known as a lymph node biopsy. It is done under an anaesthetic. Afterwards, an expert pathologist will look at the cells from the lymph node under a microscope.

![Figure: A cell slide – lymphocytes and other white blood cells are stained purple](image)

If lymphoma cells are found, the pathologist will do other tests on the sample to find what type of lymphoma you have.

**Staging: finding out where the lymphoma is in your body**

If you have lymphoma, you will need more tests to find out what parts of your body are affected by the lymphoma. This is called ‘staging’. Knowing the stage of your lymphoma helps specialists plan the best possible treatment for you.

The tests you have depend on what type of lymphoma you have and how it is affecting you. Your doctor orders only the tests you need. You might not have the
same tests as other people, even if they have the same diagnosis as you. Tests you might have include:

- **blood tests**
- chest X-rays
- scans, such as a **computed tomography (CT)** or a **positron-emission tomography (PET) scan**
- a **bone marrow biopsy**
- a **lumbar puncture**.

Some of these tests, like the bone marrow biopsy and the lumbar puncture, are done under an anaesthetic. They might be done at the same time as your biopsy.

There are different staging systems, but in all of them the stages of lymphoma range from 1 to 4, with 1 being the earliest and 4 being the most advanced stage. You might also see the stage referred to by using roman numerals: I, II, III or IV.

Many people have stage 3 or 4 (advanced-stage) lymphoma when they are diagnosed. This does not mean they have a bad outlook. There are good treatments available for all stages of lymphoma.

You should be told the type and stage of your lymphoma when you have had all your tests. It is important that you know what type of lymphoma you have, so you only look at information that is relevant for you.

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**Types of lymphoma in young people**

There are over 60 different subtypes of lymphoma, which are split into two main groups:

- **Hodgkin lymphoma**
- **non-Hodgkin lymphoma** (NHL).

Hodgkin lymphoma is much more common than non-Hodgkin lymphoma in young people.

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Figure: Around one-third of young people diagnosed with lymphoma have a type of non-Hodgkin lymphoma; the remaining two-thirds have Hodgkin lymphoma
There are lots of types of lymphoma within these groups. The different types of lymphoma can develop from different types of **lymphocyte**:  

- B-cell lymphomas develop from B lymphocytes (also called ‘B cells’)
- T-cell lymphomas develop from T lymphocytes (also called ‘T cells’).

Lymphomas can also be divided into high-grade (fast growing) or low-grade (slow growing) types. Most young people have high-grade lymphomas. This may sound worrying but high-grade lymphomas are more likely to go into long-term remission (no evidence of lymphoma) than low-grade lymphomas, which tend to relapse (come back).

**Hodgkin lymphoma**

Most people diagnosed with Hodgkin lymphoma have **classical Hodgkin lymphoma**. There are four types of classical Hodgkin lymphoma and they are all treated in the same way. They are fast-growing types of B-cell lymphoma.

**Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)** is much less common. NLPHL grows more slowly and usually needs less treatment than the classical types.

**Non-Hodgkin lymphoma (NHL)**

There are many different types of NHL. The most common that occur in young people are all high-grade lymphomas:

- **Anaplastic large cell lymphoma (ALCL)**: a T-cell lymphoma that can develop anywhere in the body, either in the lymph nodes or in ‘extranodal’ sites (areas outside of the lymph nodes, for example the skin, liver, lung or bone).
- **Burkitt lymphoma**: a B-cell lymphoma that often involves lymph nodes in the abdomen (tummy) or bowel.
- **Diffuse large B-cell lymphoma (DLBCL)**: a B-cell lymphoma that can develop in lymph nodes or in extranodal sites, such as the chest, abdomen and bones.
- **Lymphoblastic lymphoma**: a T-cell lymphoma that most often causes swelling of lymph nodes inside the chest around the heart, in an area known as the mediastinum. B-cell lymphoblastic lymphoma occurs much more rarely.

Other types of lymphoma can also occur. The most common type of NHL in young adults is DLBCL.

Our pages on **types of NHL** have more details on some of these types of lymphoma, and on other types of lymphoma.
Outlook

Although no one can know for certain what anybody’s outlook is, treatments for young people with lymphoma are generally very successful.

With the right treatment, most young people who have lymphoma go into complete remission (no evidence of lymphoma) and stay in remission.

Be careful if you look at statistics. A lot of statistics are very general. Cure rates in young people are much higher than in older people and are improving all the time. Your lymphoma specialist is the best person to talk to about your chance of cure, as they know your individual circumstances.

Treatment

There are UK guidelines setting out the ‘best’ treatment for each type of lymphoma, but your treatment is planned individually. Your treatment will depend on the type and stage of your lymphoma and other factors, including your age and general health.

- Most people will have chemotherapy.
- Some people, often those with Hodgkin lymphoma, will have radiotherapy.
- Some people will have antibody therapy as well as chemotherapy.
- People with lymphoblastic lymphoma are usually treated with intensive blocks of chemotherapy followed by a maintenance period where less intensive treatment is given to mop up any remaining lymphoma cells.

There is more about each of these types of treatment in the sections below, and you can follow the links to find more detailed information about these treatments.

We can’t tell you which treatment you should have, as it depends on your individual circumstances. Your lymphoma specialist is the best person to talk to about the possible treatments for your lymphoma.

Find out more about where you will be treated and who is involved in your care on our page of practical advice for young people with lymphoma.

Chemotherapy

Chemotherapy means treatment with medicines or drugs. It is often called ‘chemo’ for short.

Usually several drugs that each kill cancer cells in a slightly different way are combined together in a ‘regimen’. These regimens are often known as abbreviations of the names of drugs they include, for example OEPA, COPDAC or ABVD. Each letter stands for one of the drugs in the regimen.
Many chemo drugs have to be given intravenously (through a drip into a vein). This can be through a cannula, which is a soft tube that is put into your vein using a needle. Cannulas need to be taken out and replaced between treatments. Many people have a central line fitted so they don’t need to have a needle every time they need treatment. There are different types of central line but they are all thin, soft tubes that stay in your vein throughout your treatment.

You might have to take some medicines as tablets or capsules as part of your treatment.

If you have NHL, you might have some of your treatment intrathecally (by lumbar puncture into the space around your spinal cord). This helps to prevent the lymphoma spreading to your central nervous system (brain and spinal cord).

Chemo is given in cycles. A cycle is a block of chemo that is followed by some time off treatment to let your body recover. A recovery period is needed because chemo kills healthy cells as well as lymphoma cells and it takes time for the healthy cells to build back up. You usually have most of your chemo as an outpatient, but you might need to stay in hospital (as an inpatient) for monitoring sometimes.

The amount of time it takes to finish chemo depends on what treatment is planned and how your body responds to it. It can take anything from a few weeks up to 2 years to complete. You are monitored closely throughout treatment. Your medical team check how much lymphoma has been killed and how well your body is coping with the treatment. If your body doesn’t recover as quickly as hoped, the next cycle of chemo might need to be delayed until it is safe for you to have more treatment.

**Radiotherapy**

*Radiotherapy* is not often used for NHL in young people, unless it is used to treat any big clumps of lymphoma in your body. Some young people with Hodgkin lymphoma have radiotherapy.

Radiotherapy uses powerful X-rays focused on the lymphoma cells to kill them. The type of radiotherapy used in lymphoma treatment doesn’t make you radioactive. You can still be close to other people after having radiotherapy.

The lowest possible dose of X-rays is used to reduce your chance of late effects (side effects that occur months or years after treatment).

The radiotherapy is given over several days or weeks, but each treatment only lasts a few minutes. You need to keep very still for these few minutes. Although the treatment time is short, appointments can take a while. The X-ray beam has to be carefully positioned so that it gets all the lymphoma cells but as few of your healthy
cells as possible. Ink marks or tiny tattoos will be made on your skin to make sure the same area is treated every time.

**Antibody therapy**

Your body makes antibodies naturally to fight infection. Each antibody sticks to a target (a certain protein) on cells, such as bacteria, and tells your body to get rid of those cells. Laboratory-made antibodies work in the same way and attach to a specific target to tell your body to destroy it.

In **antibody therapy**, laboratory-made antibodies are used to kill lymphoma cells. The following treatments are mainly used in people over 18 but are being tested, or starting to be used, for people under 18 too.

- **Rituximab** is an antibody therapy that sticks to B cells. It is used to treat many types of B-cell lymphoma, for example Burkitt lymphoma and DLBCL.
- **Brentuximab vedotin** is an antibody joined to a chemotherapy drug. It takes the chemotherapy drug directly to the lymphoma cells so it can kill them. It is used for some people with Hodgkin lymphoma or ALCL that has come back or didn’t respond to previous treatments.

**Clinical trials**

Your specialist might ask you whether you would like to enter a **clinical trial**. Trials are scientific studies that test medical treatments on human volunteers. They are a way for specialists to work together to find out more about a particular illness and the best way to treat it. Many trials aim to limit side effects, especially in the long-term, while still giving every chance of making the lymphoma go into remission. Different trials have different aims. These include (but are not limited to):

- finding the right amount of treatment to give, depending on how quickly the lymphoma is growing and how well the person is responding to the treatment
- comparing different regimens to find out if newer regimens are more effective at killing the lymphoma cells than the standard regimen and if they have fewer side effects
- testing new treatments that have been developed to kill lymphoma cells but might cause less damage to healthy cells.

Ask your lymphoma specialist if you would like more information about clinical trials. You don’t have to take part in a clinical trial if you don’t want to. If you do decide to take part, you can change your mind at any time. If you choose not to take part in a clinical trial, or you start one and decide not to continue, that is your decision, and your specialist will use the best available standard treatment.
Side effects and late effects of treatment

Treatment is given with the aim of killing lymphoma cells, but it also damages some of your healthy cells. This can cause unwanted effects on your body, known as side effects.

Most side effects are short-term but some of them can be longer lasting. Some of them only become apparent weeks, months or even years after treatment (late effects).

Your medical team will give you information on all the drugs and treatments that they are recommending, including details of any side effects that can happen.

Side effects that commonly occur during lymphoma treatment are:

- nausea and vomiting
- hair loss
- effects on the blood: neutropenia, anaemia and thrombocytopenia
- sore mouth and throat
- weight loss or gain.

Antibody therapy is a targeted type of treatment and is designed to have fewer effects on healthy cells than other types of treatment. The most common side effects happen soon after treatment begins and can include fever, chills and shivering. These effects are most common with your first dose. Antibody therapies can cause other side effects too, like low blood counts (low levels of different types of blood cell).

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For my own mental sanity, I weirdly wanted to be ill. I needed the confirmation that the drugs were working.
Natalia, diagnosed at 20

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Most people recover well from their treatment for lymphoma without any long-term effects. However, in some people, chemotherapy and radiotherapy can cause late effects such as:

- fertility problems
- other cancers later in life
- increased risk of heart disease and stroke
- lung problems.

If you have radiotherapy while you are still growing, your growth may be affected.
Everyone responds differently to treatment, so it is difficult to predict exactly what side effects you will get. You are monitored carefully for side effects throughout your treatment. Speak to your medical team if you have any side effects. They can give you treatments and advice to help.

Ask about the risk of late effects, too. There may be ways to preserve your fertility if you need to have a treatment that is likely to reduce fertility. You should also make sure you are aware of any symptoms to look out for later in life, and any screening programmes you should take part in. For example, you might need earlier breast screening if you’ve had radiotherapy to your chest.

My new chemotherapy had a higher risk of infertility, so my doctor referred me to a different hospital that was more specialised in fertility.

Rebekah, diagnosed at 18, had ovarian tissue preservation when she had to switch to a stronger chemotherapy.
What happens if lymphoma comes back or doesn’t respond to treatment?

You might want to skip this section if it doesn’t apply to you – most young people are successfully treated for lymphoma and stay in remission.

Sometimes lymphoma does relapse (comes back after treatment).

For a small number of young people, the first treatment course isn’t enough to put their lymphoma into remission. In this case the lymphoma is called ‘refractory’, and you will probably need a stronger treatment. Some people are changed to a stronger treatment part-way through their treatment course.

If your lymphoma has come back or hasn’t responded to treatment, you might be offered:

- a different, probably stronger, chemo regimen
- high-dose chemo followed by a stem cell transplant to help your body recover after the strong chemo
- a targeted drug, possibly as part of a clinical trial.

There are some treatments specifically approved for people with relapsed or refractory lymphoma. For example, brentuximab vedotin is used for people with Hodgkin lymphoma or ALCL who have already had other treatments.

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After I was diagnosed, I was treated with ABVD chemotherapy. A few months after my treatment finished, I relapsed. I was given stronger treatment in the form of ESHAP high-dose chemotherapy, a stem cell transplant (using my own stem cells) and radiotherapy. The stronger treatment did the trick and I have been in remission for almost 10 years.

Sam, diagnosed at 23
After treatment

You have **scans and tests** during and at the end of treatment to make sure that you are in remission.

Once treatment is finished and you are in remission, you need to go for regular check-ups at the hospital for the next few years. This is called ‘**follow-up**’. Your doctors check that the lymphoma has not come back. They want to see that you are recovering well, too, and if there is anything they can do to support your recovery.

The few months that follow a lymphoma diagnosis can be very difficult, and it can take time after your recovery to come to terms with what has happened. Many people struggle with their feelings at this time. It is natural to need a period of adjustment while trying to move forward with life after lymphoma.

There are many ways that you can **get support**, both emotional and practical. Read our **practical advice page**, which explains how you can look after yourself and gives more information about where you can be treated.

You may also like to read our **Young person’s guide to lymphoma**. This booklet is designed and illustrated for young people (teens and young adults) affected by lymphoma. You can read this on our website or order a free copy.

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**Having lymphoma has changed my perspective on life. I really treasure things that come my way. A teenage cancer diagnosis has made me more socially aware and keener to get involved with fundraising and giving back to society.**

Ellie, diagnosed with Hodgkin lymphoma at 15
References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

Acknowledgements

- With thanks to Dr Catherine Hildyard, Consultant Haematologist, and Dr Georgina Hall, Consultant Paediatric Haematologist, Oxford University Hospitals NHS Trust, for reviewing this information.
- We would like to thank the members of our Reader Panel who gave their time to review this information.

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