

## Lymphoma and HIV

This page gives an overview of human immunodeficiency virus (HIV) and lymphoma. It is for people who have HIV and want to know more about their risk of developing lymphoma, or who have been diagnosed with lymphoma and want more information about what happens next and where to go for more information and support.

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**Most people who develop lymphoma do not have HIV.** However, some people with HIV develop lymphoma and some people who have lymphoma may also be diagnosed with HIV. People with lymphoma do **not** have a higher risk of developing HIV than people without lymphoma.

It is important to know that advances in the treatment of both HIV and lymphoma mean that the outcome for both has improved greatly in recent years and continues to improve all the time.

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## About HIV and lymphoma

HIV is a type of virus called a 'retrovirus'. It weakens your **immune system** by destroying a type of immune cell called a 'CD4 + **T cell**'. Without these T cells, other cells in your immune system, such as **B cells**, can't work properly. This makes it harder for your body to fight infections.

Some infections are linked to certain types of cancer. If you have HIV, you have a higher risk of developing infections and a higher risk of developing these cancers.

**Lymphoma** is a type of cancer that affects your **lymphatic system**. Some types of lymphoma are linked to infection with **Epstein-Barr virus** (EBV). These lymphomas are the most common type of cancers in people with HIV.

Lymphoma also develops in people who do not have HIV. Most people who develop lymphoma do not have HIV.

### Risk of developing lymphoma if you have HIV

A person with HIV is 10 to 20 times more likely to develop non-Hodgkin lymphoma and about 8 times more likely to develop Hodgkin lymphoma than a person without HIV.

You might see much higher risks listed on some outdated websites and reports. This is because the risk of developing non-Hodgkin lymphoma in people with HIV has reduced dramatically since antiretroviral therapies (ART; drugs that keep HIV under control) were introduced. ART prevents about two-thirds of cancers in people with HIV.

ART does not seem to have reduced the risk of developing Hodgkin lymphoma. Scientists think this might be because Hodgkin lymphoma is not as closely associated with very low immune function as non-Hodgkin lymphoma.

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## Being diagnosed with lymphoma and HIV

If you are diagnosed with lymphoma and your HIV status is not known, you may be offered an HIV test. This is standard practice in many hospitals. Most people with lymphoma do **not** have HIV. However, if you do have HIV, it is important that your medical team knows about it so that they can work with HIV specialists to offer you the best treatment for both conditions.

If you are diagnosed with lymphoma and HIV, it can feel very daunting. You do not have to face your diagnosis alone. There are **many organisations** that can help you. Your hospital may also be able to direct you to support available in your area.

It is important to know that there are treatment options for both HIV and lymphoma. **Antiretroviral therapies (ART)** are very effective at keeping HIV under control. **Lymphoma treatments are as effective in people with HIV as they are in people without HIV.**

If you are diagnosed with lymphoma and HIV, you might be referred from your local hospital to a more specialist centre. This way, experts in lymphoma and experts in HIV can work closely together to make sure you have the most suitable treatment. It may mean you need to travel further, but you have access to more expert care. You can discuss your options with your medical team.

You are usually looked after by a **multidisciplinary team** of healthcare professionals. You have a named key worker as your main point of contact. This is often a specialist haematology (specialising in blood disorders) nurse or clinical nurse specialist (CNS). They should tell you how information about your care is communicated between your HIV and lymphoma specialists. Your key worker may also be able to help you get any **support** you need.

If your friends and family don't know you have HIV, you might be worried they will find out because of your lymphoma diagnosis. Remember that most people who are diagnosed with lymphoma do not have HIV. There is no reason for people to assume you have HIV just because you have lymphoma. You are the best judge of who to tell about your HIV status. It may be helpful for you to talk to your friends and family about your HIV if you can. You may find that they are able to offer you better support if they know your situation.

If you don't want other people to know, discuss this with your medical team. People involved in your care need to know about your HIV, but they are bound by confidentiality: they can't share this information with your friends and family unless you tell them to. If you want to talk to your friends and family about your HIV, your medical team can support you in doing this.

Your medical team are likely to ask you for permission to inform your GP about your diagnosis. This allows your GP to give you the most appropriate care. Your GP must also keep your diagnosis confidential and is not allowed to tell anyone about your diagnosis without your permission.

# Types of lymphoma in people with HIV

Several different types of lymphoma are more common in people with HIV than people without HIV. These include **high-grade** (fast-growing) **B-cell non-Hodgkin lymphomas** and **Hodgkin lymphomas**.

## High-grade B-cell non-Hodgkin lymphomas

**Burkitt lymphoma** is the most common lymphoma in people with HIV. It accounts for around 45% of HIV-related lymphomas. People with HIV are around 20 times more likely than people without HIV to develop Burkitt lymphoma.

**Diffuse large B-cell lymphoma (DLBCL)** is around 10 times more common in people with HIV than people without HIV. About 35% of HIV-related lymphomas are DLBCL. Two particular subtypes of DLBCL are more common in people with HIV:

- **Primary central nervous system (CNS) lymphoma** is a type of DLBCL that starts in the brain, spinal cord and optic (eye) nerves.
- **Plasmablastic lymphoma (PBL)** is a very rare form of DLBCL that is strongly associated with HIV, although it can develop in people with other immune system disorders. In around 4 in 20 cases, it develops in the mouth, although it can affect other areas of the body. Around 2% of HIV-related lymphomas are PBL.

**Primary effusion lymphoma (PEL)** is a very rare form of non-Hodgkin lymphoma that grows in the cavities of your body (for example, around your lungs or in your tummy) without forming a mass. It is linked to infection with the human herpes virus. PEL mainly affects young people with HIV but it can develop in people with other immune system disorders or liver disease. Around 2% to 4% of HIV-related lymphomas are PEL.

## Hodgkin lymphoma

Around 5% of cancers in people with HIV are **Hodgkin lymphomas**.

## AIDS-defining cancers

Acquired immune deficiency syndrome (AIDS) is an advanced stage of HIV. It is diagnosed when a person with HIV develops one or more serious illnesses called 'AIDS-defining illnesses'.

Some types of cancer are AIDS-defining. If you have HIV and you develop one of these cancers, you are diagnosed with AIDS. In the past, people with AIDS had a poor outlook. However, effective treatment is available and the outlook has improved for most people with AIDS.

Several types of non-Hodgkin lymphoma are AIDS-defining:

- **Burkitt lymphoma**
- **diffuse large B-cell lymphoma (DLBCL)**, including plasmablastic lymphoma (PBL)
- **primary central nervous system (CNS) lymphoma.**

It is important to note that these are only AIDS-defining if you have HIV. Most people who develop these types of lymphoma do **not** have HIV and are **not** diagnosed with AIDS.

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## Symptoms of lymphoma in people with HIV

The **symptoms** of lymphoma depend on where your lymphoma is and what type of lymphoma you have. The most common types of lymphoma in people with HIV are **high-grade** (fast-growing), so symptoms can come on quickly, over a few weeks.

Initially, most people find a lump or swelling, often in the neck, armpit or groin. This is a **swollen lymph node** (gland) where abnormal cells collect. If lymph nodes deep within your body swell, you can't feel the lump from the outside but you might get other symptoms.

In people with HIV, lymphoma is often found outside of the lymph nodes, for example in organs (**spleen**, liver, lungs, kidneys), **bone marrow** (the spongy tissue in the centre of your bones where blood cells are made), or body cavities. If you have lymphoma that grows in your abdomen (tummy) or bowel, you might get **abdominal symptoms** like abdominal pain, swelling, nausea (feeling sick), vomiting or diarrhoea. Lymphoma can also develop in the **chest**, which might cause a cough or shortness of breath.

Many people with lymphoma and HIV also have **B symptoms**, which are a set of general symptoms that often occur together:

- unexplained weight loss
- fevers (temperature over 38°C)
- night sweats.

People with HIV are more likely than people without HIV to be diagnosed with lymphoma that is at an **advanced stage**. Lymphoma can also behave more aggressively (grow faster) in people with HIV than in people without HIV. This might sound alarming, but standard treatments can be used for most people and they are often very effective. Many types of lymphoma respond well to treatment, even if they are at an advanced stage when they are diagnosed.

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## Treatment of lymphoma in people with HIV

**Treatment for lymphoma** in people with HIV is the same as treatment for lymphoma in people without HIV. However, if you have HIV, you might need to be monitored more closely than people without HIV because you have a higher **risk of infection**.

You might have:

- HIV treatment
- lymphoma treatment
- treatment to prevent infections.

Your medical team should give you information about the treatment plan they recommend. You can ask as many questions as you need to – for example about your **treatment**, possible **side effects** and the likely prognosis.

Tell your medical team about any medications you are taking, including supplements and recreational drugs. Your medical team need this information to give you the best advice and care.

### HIV treatment

If you have HIV and you are not already on treatment with antiretroviral therapy (ART), your medical team is likely to recommend that you start it.

If you are already on ART, your medical team might change the ART drugs you take to make sure they don't interact with any of your lymphoma treatments.

### Lymphoma treatment

Most people with lymphoma and HIV are treated with **chemotherapy**. If you have a B-cell lymphoma that makes a protein called CD20, you also have an **antibody therapy**, such as **rituximab**. Drugs that more precisely target lymphoma cells, known as **targeted drugs**, are effective for some types of lymphoma and might be included in your treatment.

The exact treatment you have depends on a number of factors, including the **type** and **stage** of your lymphoma, whether you have any other illnesses, your immune function, and your general health.

You can read more about the treatment for the more common types of lymphoma on our separate pages:

- **Burkitt lymphoma**
- **diffuse large B-cell lymphoma (DLBCL)**
- **primary central nervous system (CNS) lymphoma**
- **Hodgkin lymphoma.**

Primary effusion lymphoma (PEL) can be difficult to treat. The most common treatment is a **chemotherapy regimen** (combination of drugs) called **CHOP**. However, people with PEL tend to have lower immune function than people with other types of lymphoma and are more likely to experience **side effects** of treatment. Research is looking at whether targeted drugs such as **lenalidomide** or **bortezomib**, or antiviral drugs such as **cidofovir** or **valganciclovir**, might be better treatment options for people with PEL. You might be able to take part in a clinical trial, although some trials exclude people who have HIV. Ask your medical team if there are any trials that might be suitable for you, or find out more about clinical trials at **Lymphoma TrialsLink**.

Plasmablastic lymphoma (PBL) can also be difficult to treat. Treatment usually involves intensive chemotherapy regimens such as **DA-EPOCH**, **CODOX-M**, **IVAC** or **hyper-CVAD**. Research is looking at whether adding **bortezomib** to chemotherapy might be effective. People who respond to chemotherapy might also have a **stem cell transplant**.

Depending on the type of lymphoma you have, you might have extra **treatment to prevent the lymphoma spreading to your central nervous system** (brain and spinal cord). This might be given as an injection in your back that goes directly into your cerebrospinal fluid (CSF – the fluid that surrounds your brain and spinal cord).

## **Treatment to prevent infections**

Treatment for lymphoma and lymphoma itself can reduce your **white blood cell counts**. People with HIV already have suppressed (lowered) immune systems because of HIV. This means you have a higher **risk of infection** than people without HIV. You are particularly susceptible to infections if you have **neutropenia** (a low number of white blood cells). However, you can get infections even if you do not have neutropenia.

You might need treatment to prevent infections developing.

- You might have antifungal, antiviral or antibiotic treatment to reduce your risk of infection during chemotherapy.
- If your CD4+ T cell count is very low, you may need **growth factors** to help boost your **neutrophil** count and reduce your risk of infection.
- You might also be monitored to make sure any infections that could be lying dormant in your body don't reactivate.

**If you notice any **signs of infection**, contact your medical team straightaway.**

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## Outlook of lymphoma in people who have HIV

Your prognosis (outlook) depends on your individual circumstances, such as the **type of lymphoma** you have, your immune function, and your general health and fitness. Your medical team can give you information about your particular outlook.

Since ART was introduced, the outlook for people with lymphoma and HIV has improved greatly. In general, lymphoma treatments are just as effective in people with HIV as they are in people without HIV.

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## Relapsed or refractory lymphoma

In many cases, chemotherapy leads to **remission** (no evidence of lymphoma) regardless of someone's HIV status. Sometimes lymphoma **relapses** (comes back after treatment) and in some cases it is **refractory** (it doesn't respond to the first treatment). These types of lymphoma are more difficult to treat, although many cases can be treated successfully with more intensive chemotherapy. For example, you might be offered a different **chemotherapy regimen** (combination of drugs), possibly at a higher dose, or your medical team might recommend a **stem cell transplant**.

There may also be a clinical trial you can enter. If you're interested, ask your medical team if there is a trial suitable for you. You can also search **our database of clinical trials** open for people with lymphoma in the UK. Many clinical trials exclude patients with HIV, but this is changing and some lymphoma trials include people with HIV.

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# Looking after yourself if you have lymphoma and HIV

Taking good care of yourself will help you through your treatment and aid your recovery. There are many things you can do to look after yourself throughout your treatment for lymphoma and beyond. We outline some of them below.

## Look out for signs of infection

Your medical team should tell you what **signs of infection** to look out for. They should also give you telephone numbers to call at any time if you think you might have an infection. Ask for these if you have not been given them.

**If you notice any **signs of infection**, contact your medical team straightaway.**

## Practise safe sex

Anyone having chemotherapy should use barrier contraception (for example, condoms). Chemotherapy can stay in your system for several days. Barrier contraception protects your partner from exposure to your chemotherapy. Treatments for lymphoma may also damage eggs and sperm or an unborn baby. People are usually advised to wait up to 2 years after having lymphoma treatment before trying for a baby.

Condoms also help prevent you passing HIV to your partner. Ask your medical team for advice on contraception if you have any concerns.

## Get vaccinated

**Vaccinations** can protect you against infections. Everyone should keep their vaccinations up-to-date. People with HIV are recommended to have a flu vaccination and a pneumococcal vaccination every year. Live vaccines (vaccines that are made using bacteria or viruses that are weakened but still alive) are not recommended for people with lymphoma.

**The NHS** has more information about vaccinations.

## Look after your body

Keeping in good health can improve how you feel in yourself. It can also help with your recovery after treatment. Read our section on **living with lymphoma** for advice on physical health, emotional wellbeing, day-to-day practicalities and travel.

The following tips are general advice to help you improve your health:

- **Exercise regularly.** Even going for a walk can help.
- **Try to stop smoking** if you are a smoker.
- **Drink alcohol within the national drinking guidelines.**
- **Avoid recreational drugs.** Your HIV team can give you honest advice and guidance around the use of recreational drugs.
- **Eat a healthy, balanced diet.** Your medical team may be able to put you in touch with a dietitian if you have problems with eating.

The **NHS** also offers advice and guidance on many of these topics.

## Take care of your emotional wellbeing and mental health

Your **emotional wellbeing and mental health** are very important. Your feelings are likely to vary from day-to-day. Ask your medical team for advice on what support is available in your area. There are many **organisations** that support people in a similar situation and can help you work through your feelings. Friends and family can also be a useful source of support.

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## After treatment for lymphoma

After your lymphoma treatment finishes, you have check-ups at the hospital. This is called **follow-up**. The aim of follow-up is to support you during your recovery and to make sure your lymphoma hasn't relapsed.

Your follow-up depends on your individual circumstances, such as the type of lymphoma you've had, the treatment you received, your general health and the usual practice at your hospital. At some hospitals, you book your own follow-up appointments as-and-when you feel you need them. At others, you have regular scheduled appointments. Whichever type of follow-up you have, you can always contact your medical team if you have any concerns.

For many types of lymphoma, the risk of your lymphoma relapsing decreases as time goes on. After 2 years or more, you may be discharged to the care of your GP. Your GP can refer you back to your lymphoma team at any point if necessary.

You will be followed-up as normal by your HIV clinic.

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## Further information and support

If you would like to talk to other people in a similar situation, there are local support groups and online forums for people with HIV. Lymphoma Action offers **support groups** and an online **community forum** for anyone who has lymphoma, including people who also have a diagnosis of HIV.

Your HIV clinic is a good place to find out about local support that might be available to you. They can provide you with details of counselling services or helplines that allow you to discuss your concerns and help you to deal with your feelings about your condition.

We have a separate **list of organisations** that specialise in helping people with lymphoma, including organisations that provide information and support for people with HIV.

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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).

## 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.

## Acknowledgements

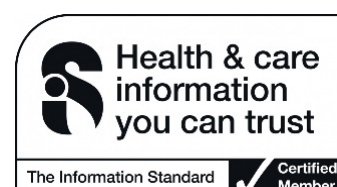
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