### Lymphoma and HIV

Lymphoma is a common type of cancer diagnosed in people with human immunodeficiency virus (HIV). This information sheet gives an overview of what to expect and where to find more information and support if you are affected by HIV and lymphoma.

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You might be someone with HIV who wants to know more about your risk of developing lymphoma, or you might have been diagnosed with lymphoma and want more information about what happens next. It is important to know that the advances in the treatment of both HIV and lymphoma made in recent years mean that the outcome in both has improved and is continuing to improve.

If you have been diagnosed with lymphoma and are not known to be HIV positive, you are commonly 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 doctors know about it so that they can work with HIV specialists to offer you the best treatment for both conditions.

A double diagnosis of lymphoma and HIV can feel very daunting. You do not have to face your diagnosis alone. Many organisations help people with each of these conditions. Your hospital may also be able to direct you to support available in your area.
Please remember that there are treatment options for both of these conditions. Antiretroviral therapies (ART) are very effective at keeping HIV under control, which helps prevent HIV-related illnesses as well as reduce the risk of passing HIV on to other people. Antiretroviral treatment now means that people living with HIV have a near normal life expectancy. HIV medications and supportive care (treatment to manage side effects and symptoms) will be given throughout your lymphoma treatment.

Treatment for lymphoma is similar regardless of your HIV status. If you have HIV as well as lymphoma, you may need to have increased monitoring or take extra medications to reduce the risk of infections. Your lymphoma team will work with your HIV team.

Your medical team are likely to recommend that you give permission for them to inform your GP about your conditions and recommended treatment. This allows your GP to give you the most appropriate care. It doesn't affect confidentiality. Your GP is not allowed to tell anyone about your diagnosis without your explicit permission.

Your prognosis (outlook) depends on your individual circumstances, such as how advanced each disease is when it is diagnosed, when it is diagnosed and your general health.

We have more information about lymphoma, which you can find on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you copies. Please email at information@lymphomas.org.uk or call on 0808 808 5555.

**Why are people with HIV at greater risk of developing lymphoma?**

A person with HIV is about 70 times more likely to develop non-Hodgkin lymphoma than a person without HIV. Similarly, someone with HIV, has a risk of developing Hodgkin lymphoma around 10 to 20 times higher than someone without HIV.

HIV is a type of virus called a ‘retrovirus’. It weakens your immune system by destroying a type of T cell (CD4+ T cell). Without these T cells, other types of cells in your immune system, such as B cells, can’t work properly.

People with HIV are less able to fight infections that are linked to certain types of cancer, including lymphoma. For example, the Epstein-Barr virus (EBV) mainly infects B cells. In some people, EBV causes changes in the infected B cells that is associated with the development of lymphoma. This risk is higher if you also have another condition that weakens your immune system, like HIV.

It is important to remember that EBV is a very common virus – around 9 in every 10 adults have had EBV. It is the same virus that causes glandular fever. The vast majority of people with EBV do not go on to develop cancer.
Many factors other than EBV infection are involved in the development of cancer. Lifestyle factors like smoking and drinking alcohol can increase the risk of developing many types of cancer. Scientists are still learning how and why lymphoma develops.

We have more information about the causes of lymphoma, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

What types of lymphoma do people with HIV get?

There are several types of cancer known as ‘AIDS-defining malignancies’. Acquired immunodeficiency syndrome (AIDS) is an advanced stage of HIV. If you have HIV and develop certain infections or cancers, you will be diagnosed with AIDS.

Please note this only applies if you have HIV – most people who develop these types of lymphoma do not have HIV and are not be diagnosed with AIDS.

In the past, people with AIDS used to have a poor prognosis. However, effective treatment that has since become available means this is no longer the case for most people. Most people newly diagnosed with AIDS are not yet on treatment for HIV.

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

- Burkitt lymphoma
- diffuse large B-cell lymphoma (DLBCL)
- primary central nervous system (CNS) lymphoma – this is usually a type of DLBCL that starts in the brain, spinal cord and optic (eye) nerves.

The most commonly diagnosed types of lymphoma amongst people with HIV are Burkitt lymphoma and DLBCL.

Some very rare types of non-Hodgkin lymphoma are also more common in people with HIV, eg:

- primary effusion lymphoma, which grows in the cavities in your body without forming a mass
- plasmablastic lymphoma, a form of non-Hodgkin lymphoma that can grow in the mouth or at other sites in people with HIV.

Since the introduction of ART for HIV, the risk of developing these AIDS-defining forms of lymphoma has reduced. However, there has been an increase in the risk of developing other types of lymphoma, eg Hodgkin lymphoma. Scientists are not sure why and many groups are investigating it.
The outcome for people with HIV treated for lymphoma is much better since ART has been introduced and your team is likely to recommend you have ART during your treatment for lymphoma.

We have more information about the most common types of lymphoma, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

What are the symptoms of lymphoma?

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 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. Many people with HIV have lymphoma that grows in their abdomen (tummy) or bowel. If this is the case, you might get symptoms like abdominal pain, swelling, nausea (feeling sick), vomiting or diarrhoea.

You might also have B symptoms, which are a set of general symptoms that often occur together:

- weight loss
- fevers
- night sweats.

In people with HIV, lymphoma is often found outside of the lymph nodes, eg in the organs (liver, lungs, kidneys) or bone marrow.

People with HIV are more likely than others to be diagnosed when their lymphoma is at an advanced stage or is found outside of lymph nodes (extranodal). This might sound alarming, but many types of lymphoma respond well to treatment when given with ART as well, even if they were at an advanced stage.

We have more information about the symptoms of lymphoma and about staging of lymphoma, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.
How will I be treated?

Depending where you live, your doctor might recommend that you are referred from your local hospital to a more specialist centre. This way, experts in lymphoma and experts in HIV can work closely together to manage both conditions. It may mean that you need to travel further, but you would have access to more expert care. You can discuss your options with your doctor.

You are usually given a key worker who can be your point of contact between different experts. Your key worker is often a specialist haematology (specialising in blood disorders) nurse. You might also hear the term clinical nurse specialist (CNS). Your key worker may also be able to help you get any support you need.

Most people with lymphoma and HIV are treated with chemotherapy combined with ART. Newer, targeted drugs that target lymphoma cells more precisely might help some people. Ask your doctor if there are any clinical trials suitable for you.

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

If you are not already receiving treatment for your HIV, you are strongly recommended to start ART. This is to help support your immune system during your lymphoma treatment. If you are already receiving ART, your doctor may need to change the drugs you are on. This can prevent drug interactions that could give unwanted side effects or cause your treatments to be less effective.

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.

You are likely to get supportive treatments to reduce your risk of complications during treatment for lymphoma. White blood cells, such as neutrophils, fight infection but chemotherapy affects them, too. Growth factors, like granulocyte-colony stimulating factor (G-CSF), are given to help your blood cell counts recover after chemotherapy. It is important to take measures to reduce your risk of infection during your treatment.

We have more information about supportive treatments, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

You are likely to be given additional drugs such as antibiotics, antiviral or antifungal drugs to prevent infections during chemotherapy. You might also be monitored to make sure previous infections don’t reactivate (some infections can remain dormant in your body).
Depending on your treatment and general health, you might need other supportive care.

You can read more about the possible treatments for your lymphoma on our pages on each type of lymphoma for:

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

For rare lymphomas like primary effusion lymphoma and plasmablastic lymphoma, chemotherapy with a regimen (combination of drugs) like CHOP is often given. More intensive regimens may be used or other drug combinations. Some people may be able to enter a clinical trial testing newer, targeted therapies.

We have more information about treatments for lymphoma, which you can read on our website at [www.lymphomas.org.uk](http://www.lymphomas.org.uk). You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

**What are the risks if I have HIV and lymphoma?**

Although lymphoma and HIV can be managed effectively in many cases, there are some risks that are greater for people who have both conditions. Your medical team can give you more information about your risks and how they can be managed. Below we outline some of the risks that your doctor takes into account.

**Advanced lymphoma at diagnosis**

In general, in people with HIV, lymphoma is often at a more advanced stage when it is diagnosed. It can also behave more aggressively (grow faster) than in the general population. However, standard treatments can be used for most people and they are often very effective. Some studies have shown that cure rates are the same for patients who take ART during their lymphoma treatment, even if their lymphoma was at a more advanced stage when treatment started.

**Increased risk of infection**

Treatment for lymphoma and lymphoma itself reduce your white blood cell counts, making you more susceptible to infections. People with HIV already have suppressed (lowered) immune systems because of HIV. However, the risk of serious infections during chemotherapy has been greatly reduced with the use of ART therapy and good supportive care, eg growth factors to help your white blood cell counts recover.
What happens if my lymphoma comes back or doesn’t respond to treatment?

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 (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. You might be offered a different chemotherapy regimen, possibly at a high-dose. Your doctor might recommend a stem cell transplant.

There may also be a clinical trial you can enter. If you’re interested, ask your doctor if there is a trial suitable for you. Most clinical trials exclude patients with HIV, but this is changing and some lymphoma trials include people with HIV, especially the ones whose immune system isn’t severely compromised.

We have more information about stem cell transplants and clinical trials, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

How can I look after myself at this time?

Being diagnosed with lymphoma is difficult, whether you have HIV or not. Rest assured that modern drugs allow many people with HIV to manage their condition effectively and have a normal life expectancy. The combination of modern anti-HIV drugs and other supportive care allows lymphoma to usually be treated in the same way as if you were HIV-negative. What’s more, the outcomes for people with HIV are now similar to the outcomes of people without HIV.

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

Look out for signs of infection

You are at increased risk of infection during your lymphoma treatment, particularly if you also have 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.

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. Call your medical team immediately if you have any symptoms of infection.

We have more information about neutropenia and the risk of infection, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.
Look after your body and mind

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 on our website 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.

You can find more information about any of these topics on NHS Choices website at www.nhs.uk/livewell/pages/livewellhub.aspx.

Your emotional wellbeing is very important. Your feelings are likely to vary from day-to-day. Seek support from your friends and family. There are many organisations that support people in a similar situation and can help you work through your feelings. You can also ask your medical team for advice on what support is available in your area.

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 close to you to assume you have HIV just because you have lymphoma. You are the best judge of who you wish to know 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.

Practice safe sex

Anyone having chemotherapy needs to use barrier contraception (eg 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.

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 also recommended to have a flu jab every year and a pneumococcal vaccination.

NHS Choices have more information about vaccinations on their website at www.bit.do/NHS-vaccines.

What happens after treatment has finished?

When your lymphoma treatment has finished and you are in remission (no evidence of lymphoma), you are seen regularly in the hospital clinic for check-ups. This is called follow-up. The aim of follow-up is to support you during your recovery and to check for recurrence of your lymphoma.

Your follow-up depends on your individual circumstances, such as your general health and the risk of your lymphoma relapsing (coming back). For many types of lymphoma, the risk of your lymphoma relapsing decreases as time goes on and you remain in remission. Your follow-up visits normally become less frequent over time and you may be discharged. However, if you have any concerns, contact your medical team. They might want to bring your appointment forward.

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

We have more information about follow-up, which you can read on our website at www.lymphomas.org.uk. You can also print this information at home or, if you prefer, our helpline can send you a copy. Please email information@lymphomas.org.uk or ring 0808 808 5555.

Where can I find further information and support?

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.

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.

The following organisations offer information and support to people with HIV. We have a separate list of organisations that specialise in helping people with cancer.

National AIDS Trust (NAT)
The UK’s leading charity dedicated to transforming society’s response to HIV. They offer guides to everyday concerns of people with HIV.
www.lifewithhiv.org.uk
Terrence Higgins Trust
Terrence Higgins Trust have nearly 30 years’ experience of working with and advocating on behalf of people with HIV. They offer advice and support to help people with HIV manage their condition long-term. There are local centres across the UK and the head office is based in London.

314-320 Gray’s Inn Road
London WC1X 8DP
0808 802 1221 (adviser)
020 7812 1600 (switchboard)
www.tht.org.uk/myhiv
info@tht.org.uk

NAM Aidsmap
NAM aim to provide independent, clear and accurate information about HIV and AIDS.
www.aidsmap.com

Positively UK
Peer-led support, advocacy and information for women, men and young people living with HIV. Positively UK aims to help people manage any aspect of their diagnosis, care and life with HIV.

345 City Road
London EC1V 1LR
020 7713 0444 (helpline staffed by people who are HIV-positive)
positivelyuk.org
info@positivelyuk.org

AVERT
One of the world’s leading online providers of HIV and AIDS information.
www.avert.org/what-we-do/about-avert

iBase
HIV treatment information including treatment guides.
i-base.info

Sources used

These are some of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at publications@lymphomas.org.uk or call on 01296 619409 if you would like a copy.

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We continually strive to improve our resources for people affected by lymphoma and we would be interested in any feedback you might have about this information. Please visit www.lymphomas.org.uk/feedback or email publications@lymphomas.org.uk if you have any comments. Alternatively please phone our helpline on 0808 808 5555.

If you have found this information useful and would like to help make it available to other people coping with lymphoma, then please consider making a donation to support our work at www.lymphomas.org.uk/donate. We rely totally on voluntary donations. Thank you.
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