Non-Hodgkin lymphoma is one of the two most common cancers in people living with HIV in the UK (the other is Kaposi’s sarcoma), and it is the sixth most common in the general population. The damage HIV does to the immune system makes people living with HIV more vulnerable to NHL than other people.

Cancers are diseases of cells in the body. It is normal for cells to be replaced by a process of cell division, in which a cell divides and makes a new copy of itself. However, if cells start to divide in an abnormal way or if damaged cells survive when they should die, abnormal cells build up and can form a cancer.

Non-Hodgkin lymphoma (NHL) is a cancer of lymphocytes. These are white blood cells that help to fight infections. Lymphocytes travel around your body in your lymphatic system, which is part of your immune system. The lymphatic system includes lymph nodes (glands) as well as organs of your immune system like your thymus, spleen and bone marrow.

Healthy lymphocytes collect in your lymph nodes ready to fight infection. There are groups of lymph nodes in the neck, armpits, groin, chest and abdomen – they often swell when they are fighting an infection.

In NHL, lymphocytes keep dividing and grow out of the body’s control. Over time, the number of abnormal lymphocytes increases and abnormal lymphocytes collect in your lymph nodes, or elsewhere in the body.
There are many different types of NHL. The type of NHL you have may determine which type of treatment is most suitable for you. In people with HIV, the most common types of NHL are called diffuse large B-cell lymphoma (DLBCL) and Burkitt lymphoma (BL).

As well as non-Hodgkin lymphoma, you may also hear about Hodgkin lymphoma. This is a different cancer of the lymphocytes and is treated in a different way.

**Non-Hodgkin lymphoma in people living with HIV**

People with weakened immune systems, including people living with HIV, are at greater risk of having NHL than other people. People living with HIV, including people taking effective treatment, are about ten times more likely to develop NHL than people without HIV.

People with HIV who are not taking anti-HIV treatment or who have a low CD4 count are at greater risk than other people with HIV. As in the general population, older people living with HIV are at greater risk of having NHL.

People who have NHL sometimes have HIV without realising it. For this reason, it is good practice for people with NHL to be offered an HIV test, in order to rule out HIV as the underlying cause. Nonetheless, most people who have NHL do not have HIV. For most people with NHL, a specific cause cannot be identified.

People with HIV are more likely than other people to be diagnosed when their lymphoma is at a more advanced stage. It may also behave more aggressively (grow faster) than in other people and may be found outside the lymph nodes, for example in the bone marrow, liver or lungs.

In a person living with HIV, NHL may be described as an ‘AIDS-defining’ cancer. This is because it usually occurs when the immune system has been severely weakened.

Nonetheless, it’s important to stress that treatment for NHL can be very effective in people living with HIV. Cure rates for HIV-positive people who take chemotherapy and HIV treatment are similar to those in the general population. What’s more, you can expect HIV treatment to keep you in good health for years to come.

**Symptoms**

The symptoms of lymphoma depend on where the lymphoma is and what type of lymphoma it is. You may not notice anything, but NHL can cause a painless lump or swelling, often in the neck, armpit or groin (a swollen lymph node).

A lymphoma in the stomach or bowel may cause indigestion, abdominal pain or weight loss. A lymphoma in the chest area may result in a cough, difficulty swallowing or breathlessness.

Weight loss, fever and night sweats may also occur. In people with lymphoma, these are
called ‘B symptoms’.

**Diagnosis and monitoring**

The most important test for diagnosing lymphoma is a biopsy. This involves a doctor or nurse taking a sample of tissue from the affected area (for example, an enlarged lymph node or bone marrow). Some people will be given a general anaesthetic and so will be asleep when it is done, while other people will only need a local anaesthetic, which numbs the area. The tissue sample is then sent to a laboratory to be checked for lymphoma cells.

"Cure rates for HIV-positive people who take chemotherapy and HIV treatment are similar to those in the general population."

You may also need a CT (computerised tomography) scan. This takes X-ray images from multiple angles, which build up a three-dimensional picture of inside your body. This allows your doctors to see how far the lymphoma has spread and if treatment is working.

A CT scan involves you lying on an examination table which slides through a large machine. You will usually need to drink or be injected with a contrasting agent (a type of dye) before the procedure.

Depending on the type of lymphoma you have, you might have a PET/CT scan, which combines a CT scan with a positron emission tomography (PET) scan. The PET scan uses low-dose radiation to measure the activity of cells in different parts of the body – it gives more detailed information about which parts of the body have active (growing) lymphoma.

Blood tests will also be needed, to measure the amounts of certain types of cells and chemicals in your blood.

**Treatment and management**

When considering your treatment options, you and your healthcare team should take into account the type of lymphoma you have, whether it is at a more or less advanced stage, which part(s) of your body are affected, your general health, and your personal priorities.

In different circumstances, different treatments may have different aims. These may be to try to cure the NHL, to control it for as long as possible, or to relieve symptoms.

You should ask your doctor about the possible benefits of a treatment, what risks and
side-effects could be involved, what other treatments are available, and what is likely to happen without treatment.

The British HIV Association’s guidelines on treating NHL in people living with HIV recommend chemotherapy and a monoclonal antibody, as well as HIV treatment.

**Chemotherapy** is the main treatment for most types of NHL. It uses strong drugs to destroy cancer cells and prevent the cancer from spreading. Chemotherapy drugs kill cells that are growing fast, including cancer cells. However, they can’t distinguish cancer cells from normal, healthy fast-growing cells in the body – this is what causes the side-effects of chemotherapy.

A combination of different chemotherapy drugs may be provided into a vein (intravenously), given as tablets, or by another method. Depending on the chemotherapy regimen, you may be able to visit the hospital as an outpatient or you might need to stay in hospital for a few days.

**Monoclonal antibodies** are man-made drugs designed to stimulate the immune system to recognise and attack cells that have a specific substance on their surface. These drugs target the lymphoma cells more precisely than chemotherapy can. The most commonly used monoclonal antibody is called rituximab, which is given as a drip into a vein.

**HIV treatment** is recommended throughout your treatment for NHL. It will strengthen your immune system and can help keep NHL under control. If you are not already taking HIV treatment, you are strongly recommended to start. If you are already taking HIV treatment, your doctor should check that there are not any drug-drug interactions between your treatments for NHL and HIV.

Treatment for NHL as well as the cancer itself can lower your levels of white blood cells (a condition called neutropenia). This makes you more susceptible to dangerous infections. Your doctors and nurses can explain what signs of infection to look out for and what to do if you think you have an infection. You may also be given other treatments to reduce your risk of infections.

It’s very important that the doctors treating your HIV and your cancer work together. Doctors involved in treating your non-Hodgkin lymphoma may include a haematologist (a doctor who specialises in treating blood cell disorders), an oncologist (a doctor who specialises in treating cancer), a radiologist (a doctor who interprets the results of scans and x-rays) and a pathologist (a doctor who examines tissue for lymphoma cells).

**You have the best chance of a good outcome if you go to a hospital that has a lot of experience of treating cancer in people with HIV.**

Depending on where you are, your local hospital may not necessarily have this experience.
Information and support

For more information, you may find these two organisations helpful:

- Macmillan Cancer Support: www.macmillan.org.uk. You can also contact their helpline team on 0808 808 0000.
- Lymphoma Action: lymphoma-action.org.uk. Their helpline team is available on 0808 808 5555.

Find out more

Kaposi’s sarcoma Simple factsheet
Taking your HIV treatment Information booklet
HIV and the immune system Basic leaflet with pictures