



Lymphoma
association

the knowledge to challenge lymphatic cancers

High grade non-Hodgkin lymphoma



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The information in this
booklet can be made
available in large print

Introduction and acknowledgements

You may be someone with high grade non-Hodgkin lymphoma. Perhaps someone close to you has high grade non-Hodgkin lymphoma. You are not alone. Nearly 9500 people are diagnosed with non-Hodgkin lymphoma in the UK each year.

This booklet aims to explain what high grade non-Hodgkin lymphomas are, how they are treated, and what side effects you might have from treatment.

High grade non-Hodgkin lymphoma is a term that refers to a range of different diseases. People often get in touch with us to ask about one kind of high grade lymphoma in particular. This booklet describes some of the individual high grade lymphomas, and how they differ from other lymphomas. We hope that this will provide people with information not easily found elsewhere.

This has made the booklet quite long, and some of the information included is quite complicated. We hope that the instructions for using the booklet on the following page help you to find what you are looking for.

The Lymphoma Association produces other booklets that discuss living with lymphoma, including information about feelings, diet, exercise and complementary therapies. Please telephone our helpline.

This information is about high grade non-Hodgkin lymphoma in adulthood. If you are a teenager or older then this booklet is for you. The Lymphoma Association produces other information about lymphomas in children. Please telephone our helpline.

We are grateful to the following people in particular for their time and assistance in reviewing this booklet:

Dr Chris Hatton, Consultant Haematologist, Oxford Radcliffe Hospitals NHS Trust, Oxford

Ms Kath Beston, Clinical Nurse Specialist, Oxford Radcliffe Hospitals NHS Trust, Oxford

Dr Kirit Ardeshta, Consultant Haematologist, University College London Hospital and Mount Vernon Cancer Centre

Ms Fiona Harwood

Mr Fred Dampier

Mr Steve Colton

Mrs Sue Colton

We would like to acknowledge the continued support of our many expert advisors, whose ongoing contributions help us in the development of our publications.

In addition to our expert advisors, we have referred to textbooks and scientific papers in the compilation of this booklet. You will find these listed at the end of the booklet.

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How to use this booklet

This booklet has been divided into three parts. You don't have to read it all at once! You might like to read a bit at a time and come back to it when you want to find out more.

1

Part One gives an introduction to lymphomas. It deals with:

- What lymphomas are
- The symptoms of lymphoma
- How lymphoma is diagnosed
- The tests you will have.

Important!
Read this bit

2

Part Two discusses the high grade non-Hodgkin lymphomas in more detail. Part Two is written for people who want to know more about their particular kind of lymphoma. It deals with:

- How lymphomas are classified
- The different kinds of high grade non-Hodgkin lymphoma, how they affect you and how they are treated.

You can skip Part Two if you like, particularly if you are not sure what kind of high grade non-Hodgkin lymphoma you have. You may like to check this with your specialist.

3

Part Three discusses the treatment of high grade non-Hodgkin lymphoma in more detail. It deals with:

- Chemotherapy
- Radiotherapy
- Antibody therapy
- Stem cell and bone marrow transplant
- The side effects of treatment
- Your hospital
- Follow up after treatment.

You will see things written in different ways throughout the booklet. This is what they mean:

Words written like this discuss what is included in the paragraphs to follow



The arrow bullet points give you directions to other parts of the booklet with more information on a particular subject.



The helpline logo indicates that you can call our helpline for more information on this subject.

Words written in a paragraph like this are summaries of the section above. You might want to just read these bits of the booklet to get the most important points.

Part One:

Introduction to lymphomas

This part of the booklet will begin with:

The lymphatic system

What lymphomas are

The cause of lymphoma

The symptoms of lymphoma

The lymphatic system

The lymphatic system is a complex network of tubes, glands and other organs such as the spleen. The tubes are called lymph vessels. The glands are called lymph nodes. We have lymph nodes and lymph vessels throughout our bodies. The lymph nodes are often found in groups, particularly under the arms, in the neck and in the groin.

The lymphatic system is part of the body's natural defence against infection – the 'immune system'.

The lymphatic system helps to transport things from place to place around your body. These things include cells and waste products. These are carried in a clear fluid called lymph. The lymph moves through the lymph vessels and lymph nodes. The lymph nodes are an important part of your immune system. Your lymph nodes 'kick start' your body's defence against infection.

The lymph carries white blood cells called lymphocytes. Lymphocytes help our bodies to fight infection.

What is lymphoma?

Lymphomas are cancers of the lymphatic system. Lymphomas happen when the white blood cells we mentioned before – the lymphocytes – become cancerous. Lymphoma is not just one illness. It is a word used to describe a wide range of diseases that all start with a cancerous lymphocyte.

Lymphomas were first identified in the 19th century by Dr Thomas Hodgkin. Lymphomas are described as either Hodgkin lymphoma (Hodgkin's disease), or non-Hodgkin lymphoma.

Non-Hodgkin lymphomas can be fast growing (high grade or 'aggressive') or slow growing (low grade, or 'indolent').

Each year, about 9400 people in the UK are diagnosed with non-Hodgkin lymphoma. This represents about 3% of all cancers. Non-Hodgkin lymphoma is slightly more common in men. It can occur at any age, but it is more common in those aged 50 and over.

How does it happen?

Lymphocytes are constantly dividing to make new lymphocytes. They also divide when they are fighting an infection. Cell division and cell death are controlled by chemical and genetic messages.

Lymphomas occur when something goes wrong with this messaging system. Some of the lymphocytes start to divide in an abnormal way, or do not die when they should. These abnormal lymphocytes make more lymphocytes that are abnormal. They collect to form lumps. These lumps very often grow in the lymph nodes. They can grow in other parts of the body too.

How will it affect my body?

The abnormal lymphocytes have the potential to spread to other lymph nodes in all parts of the body. They can also spread to organs and tissues outside the lymphatic system and start to grow there too.

Like all cancers, lymphoma will damage the health of the individual, and this will get worse if the illness is not treated.

The lymphoma cells take up energy and nutrients that are needed by healthy cells.

Lymphoma cells are produced instead of normal lymphocytes.

Lymphoma cells prevent healthy organs from doing their usual job. This means that the person's health will suffer depending on where the lymphoma is. For example, lymphoma in the bone marrow might mean that the body can't produce enough blood cells.

Cause of lymphoma

The cause of lymphoma remains unknown.

There is no evidence to suggest that anything you have done or not done has caused your lymphoma.

You can't catch lymphoma from someone and you can't give it to someone else.

Some people are more at risk of lymphoma because of another medical condition, particularly conditions that affect the immune system. For example, people who have HIV and AIDS are more at risk of non-Hodgkin lymphoma. This does not mean that you will develop HIV or AIDS if you have non-Hodgkin lymphoma.

Some kinds of lymphoma are related to common viruses.



The Lymphoma Association produces a fact sheet about the possible causes of lymphoma. Please telephone the helpline if you would like a copy

Research studies have investigated possible causes of lymphoma, such as chemicals present in the working environment or increased risk of lymphoma in some families. But it will be a long time before scientists understand this subject properly.

The symptoms of lymphoma

People get lots of different symptoms. Some people have no symptoms at all.

The most common symptom of lymphoma is a painless lump or swelling. This can be in the neck, armpit or groin, but it can happen in other places too.

A person's symptoms can vary depending on where the lymphoma is in the body.

Some possible symptoms are:

- Unusual tiredness or fatigue
- Excessive sweating at night
- Persistent flu-like symptoms
- Fevers
- Difficulty shaking off infections
- Unexplained weight loss
- Abdominal pain
- Diarrhoea or change in bowel habit
- A persistent cough or breathlessness
- Skin rash or itching

Now that we've discussed what lymphoma is, we'll move on to discuss:

Diagnosis

Staging tests

What is meant by the stage of your lymphoma

Diagnosis

The word 'diagnosis' simply means finding out what is wrong. In most cases, it is not possible for a GP to confirm whether or not you have lymphoma – not even from a blood test. Your GP will send you to a doctor at a hospital for further tests.

Biopsy

You will almost certainly have a biopsy. In most cases a biopsy is the only way to tell whether or not a lump is lymphoma.

A biopsy means the removal of cells for close examination under a microscope. These cells can be taken from an enlarged lymph node. They can also be taken from other tissues such as the bone marrow, or any tissue that seems to have something wrong with it.

Occasionally the cells will be taken using a needle and a local anaesthetic. Often a whole enlarged lymph node will be removed. This involves having a general anaesthetic and a short stay in hospital.

Often several doctors have a look at the biopsy. Other tests are performed on the cells. These tests give information about changes in cell DNA, and proteins that can be found on the cell surface. This information helps to determine what kind of lymphoma it is.

The diagnosis of non-Hodgkin lymphoma can be difficult. Pathologists who work in General Hospitals may only see a few cases a year.

It is now recommended that suspected cases of non-Hodgkin lymphoma be reviewed in specialised laboratories. Expert pathologists will then check to make sure they agree with the diagnosis.

Staging

Staging means finding out what parts of your body are affected.

Staging involves a number of tests. Don't be worried if you don't have all of these tests. Sometimes the most common tests are all that are needed to find out about your lymphoma.

Most of these tests will be done as an outpatient – in other words, you won't need to stay in hospital overnight.

Blood tests

Blood samples will be taken to give your doctor information about your general health.

Blood tests will check things like your liver and kidney function. Other blood tests give an indication of how your general health might be affected by your lymphoma. For example, your blood count gives information about the red cells, white cells and platelets in your blood.

In some cases, your doctors may wish to test you for HIV. This is because some cases of lymphoma are related to HIV.

You will have blood tests at regular intervals during your treatment and afterwards.

Bone Marrow Biopsy

The bone marrow is spongy, jelly-like tissue found in the middle of the large bones in our bodies. The bone marrow makes our blood cells.

It is common for lymphoma cells to be found in the bone marrow. A bone marrow biopsy may be needed to check for lymphoma cells.

A bone marrow biopsy involves taking a sample of bone marrow through a large needle. You will be asked to put on a

hospital gown and lie down on a table. The needle is usually inserted through the skin into the bone of your pelvis (your hip bone) following a local anaesthetic. The procedure takes around 15 – 20 minutes.

Although doctors use a local anaesthetic, this is a painful procedure. You may need to take pain-killers before and after your bone marrow biopsy. Sedatives can help too. Ask your specialist first for advice about what to take.

You may hear this test referred to as ‘bone marrow aspirate’ or ‘bone marrow trephine’. Both are types of bone marrow biopsy. A bone marrow trephine takes more tissue, which gives your doctor more information about the structure of the marrow and the cells within it.

X-rays

X-rays can be used to look at various parts of your body. For example, a chest x-ray may be used to see if there are any enlarged lymph nodes in your chest. X-rays are painless and shouldn’t take longer than a few minutes.

Scans

Scans give a more detailed picture of the body’s internal organs and lymph nodes.

A CT scan or CAT scan involves lying on a bench that moves your body into a cylinder-shaped camera. The camera takes computerised pictures of your insides. Unlike x-rays, which give a see-through picture from front to back, CT scans give a picture of your body in cross section from top to bottom. As the bench moves, the camera takes pictures of the different layers of your body.

You may be asked not to eat or drink on the morning of the scan. Most people will be given a liquid to drink, or an injection into a vein, beforehand. These are to make it easier to see some of your internal organs. The drink or injection might

make you feel hot all over but this usually only lasts a few minutes. Tell someone if you feel this way.

If you are allergic to iodine, or if you have asthma, it is important that you tell the people doing the test before you have the drink or injection.

The scan is painless, and takes 5 – 20 minutes. You will be asked to lie quite still while the pictures are being taken.

MRI (or NMR) scans are similar to CT scans, except they give a slightly different image of the internal structures of your body. MRI is particularly good at imaging certain tissues such as the brain. Like having a CT scan, you are asked to lie on a table that moves you into a cylinder. The cylinder measures magnetic waves as they pass through your body. This test takes about an hour and is painless, but can be very noisy and you may feel claustrophobic.

Because the cylinder uses a magnet, you should take off all metal jewellery beforehand. You should also let the technicians know if you have any other metal implants, such as a replaced hip or a pacemaker. Sometimes metal 'staples' are used instead of stitches after an operation, so mention this if you still have them in after your biopsy.

PET scans provide images of internal structures, but they also provide information about the activity of the cells. They can help doctors to distinguish between malignant and non-malignant cells. Like a CT scan, you will be given an injection beforehand. PET scans can take up to an hour. PET scanners are not common at the moment, and there are only a few centres in Britain that have them. They will probably become more common in the future. There are some machines that combine PET scans with CT scans, but these are not widely available at present.

An ultrasound scan may be used to check the inside of your abdomen. This scan uses sound waves that bounce off internal organs to create an image. You will be positioned on your back, and a gel rubbed onto your stomach. A technician will then pass an instrument over the gel to produce a picture on a small screen. It is a painless procedure and takes about a quarter of an hour.

Lumbar puncture

Around your brain and spinal cord is a fluid called CSF – or ‘cerebrospinal fluid’. Some kinds of high grade non-Hodgkin lymphoma can get into the CSF.

Your doctor may want to do a lumbar puncture to take a sample of your CSF using a needle and syringe. The CSF will then be examined under a microscope.

You will be positioned either on your side curled up with your knees to your chest, or sitting up and leaning forward onto a support. A doctor will feel for a gap between the bones of the ‘lumbar’ part of your spine, or the small of your back. A needle is inserted in the gap, and a little CSF is drained off.

A local anaesthetic will be used. You will be asked to keep very still. You may have to lie down for a period of time afterwards. This is because it is common to get a headache after a lumbar puncture, and the headache is made worse when sitting up.

The stage of your lymphoma

Once all the test results are ready, your doctor will be able to tell which parts of your body are affected by your lymphoma. This is called the stage of your disease. The different stages are described below.

Stage 1	One group of lymph nodes is affected on one side of the diaphragm
Stage 2	Two or more groups of lymph nodes are affected on one side of the diaphragm
Stage 3	Lymph nodes are affected on both sides of the diaphragm
Stage 4	Lymphoma can be found on both sides of the diaphragm and in organs outside the lymphatic system or in the bone marrow

In addition to the stage, you may also hear the letters ‘A’ or ‘B’ used to describe your illness. This refers to whether or not you’ve had significant weight loss, drenching night sweats or unexplained fevers. ‘B’ means that you have had one or more of these symptoms and ‘A’ means that you have not.

In some cases, lymphoma can be confined to places outside the lymphatic system. Your specialist might use different terms to describe the stage of your disease. For example, some doctors will use the letter ‘E’ for ‘extranodal’ to refer to disease that is outside the lymphatic system.

These tests can take a couple of weeks to complete. This might seem a long time, but the information being collected is very important. Your doctor needs to know as much as possible about your illness before choosing the treatment that will be best for you. It can be frustrating and worrying to have to wait before you find out more, and you may find this time difficult.

Summary

- Lymphomas are cancers of the lymphatic system. There are many different types of lymphoma.
- Lymphomas develop when a kind of white blood cell called a lymphocyte becomes malignant. The cancerous cells collect to form lumps. They can spread to other parts of the body. If this happens, they can prevent your healthy organs and tissues from working properly.
- Lymphomas are described as either Hodgkin lymphoma (Hodgkin's disease), or non-Hodgkin lymphoma. Non-Hodgkin lymphomas can be fast growing (high grade or 'aggressive') or slow growing (low grade, or 'indolent').
- The cause of lymphoma is not fully understood.
- Lymphomas often cause very few symptoms. The most common symptom is a lump or swelling. Other symptoms include weight loss, night sweats and diarrhoea.
- It is not possible for your GP to diagnose lymphoma. Lymphomas are diagnosed following a biopsy of a lump, which means taking some of the cells to look at under the microscope.
- After this, you will have lots of other tests to find out what parts of the body are involved. These include scans and blood tests, and sometimes bone marrow biopsy and lumbar puncture.
- The results of these tests will tell your specialist the 'stage' of your illness.

The next part of the booklet will discuss high grade non-Hodgkin lymphomas in more detail.

Part Two: About high grade non-Hodgkin lymphomas

2

So far, we have discussed what lymphomas are, and how they are diagnosed. This part of the booklet will discuss the high grade lymphomas in greater detail.

The first part of this section will discuss how lymphomas are put into groups. It will discuss:

B-cells and T-cells

Classification of lymphomas

What is meant by 'high grade'

B-cells and T-cells

You may recall from our earlier discussion that lymphomas happen when a lymphocyte becomes cancerous. Lymphocytes are either B-cells or T-cells. So, high grade non-Hodgkin lymphomas are either B-cell lymphomas or T-cell lymphomas.

B-cells and T-cells are so called because they grow to maturity in different parts of the body.

B-cells mature in the bone marrow.

T-cells mature in the thymus gland in your chest.

B-cells and T-cells act in different ways to protect our bodies from infection and illness.

Most lymphomas come from B-cells. B-cell lymphomas are about 10 times more common than T-cell lymphomas.

Classification

The process of classification means sorting all the different lymphomas into particular groups. Tests performed on the cells following your biopsy will help with classification. Classification depends on:

- what type of lymphocyte has become cancerous, for example, whether it is a B-cell or a T-cell
- what the cells look like under the microscope
- what 'chemicals' or 'proteins' are on the cell
- what changes have happened to the genes in the nucleus of the cell.

The classification of your lymphoma is very important. It will give your specialist vital information about your illness and what you can expect. In particular, it will tell your specialist:

- whether the lymphoma is growing quickly or slowly
- how the lymphoma might behave, for example what parts of the body might be at risk
- what kind of treatment will be needed.

What is meant by high grade?

Lymphomas are described as high grade if the cells appear to be dividing quickly. If the cells are dividing quickly, the lymphoma will grow quickly. You may also hear your doctors use the word 'aggressive' or 'histologically aggressive'.

Some lymphomas grow faster than others. The rate of cell division will vary from person to person. No two people are identical, even if 'on paper' their lymphomas are the same.



For more information about the classification of lymphomas, call the helpline for a copy of our fact file

Summary

- Lymphomas are called B-cell lymphomas or T-cell lymphomas, depending on what kind of lymphocyte has become cancerous. B-cell lymphomas are more common than T-cell lymphomas.
- Lymphomas are classified – or put into different groups – depending on what kind of cell has become malignant, and the characteristics of the T-cell.
- High grade non-Hodgkin lymphoma tends to grow quickly. Doctors also use the word 'aggressive' to describe high grade lymphomas.
- The classification of your lymphoma is very important in deciding on what treatment will be best for you.

The high grade non-Hodgkin lymphomas

This part of the booklet discusses each of the high grade non-Hodgkin lymphomas separately. For each disease, there is a table that discusses:

What the name means

Who gets it

How it will affect you


How it is treated.

Diffuse large B-cell lymphoma is the most common type of high grade non-Hodgkin lymphoma, so we have put that one first.

The other kinds of high grade non-Hodgkin lymphoma are listed alphabetically. You will find them mentioned in the index on pages 3-4.

If you are not sure what kind of high grade lymphoma you have, you can just skip this part and move on to Part 3.

We would like to stress that you might find it confusing or distressing to read about lymphomas that are not relevant to your situation. You may wish to check this with your specialist before you find out more.



Important!
Read this bit

Diffuse large B-cell lymphoma

T-cell or B-cell?	B-cell
What does it mean?	<p>Diffuse large B-cell lymphoma (DLBCL) is the most common kind of high grade non-Hodgkin lymphoma. The word 'diffuse' means that the cells are spread throughout the lymph node, compared to other lymphomas where the cells form clumps in the lymph nodes.</p>
Who gets it?	<p>DLBCL is the most common type of high grade non-Hodgkin lymphoma.</p> <p>Around 3000 people are diagnosed with DLBCL each year in the UK. It is slightly more common in men than in women. It is most likely to occur in those aged over 50.</p> <p>Sometimes, DLBCL occurs in people who have had low grade non-Hodgkin lymphoma in the past that has changed to become high grade.</p>
How will it affect me?	<p>Some people with DLBCL have disease at stage 1 or 2 when they are diagnosed. Most people will have more advanced disease at stage 3 or 4.</p> <p>It is quite common for people with DLBCL to have disease in parts of the body other than the lymphatic system. You may hear the word 'extranodal' used to describe this. For example, it is relatively common for DLBCL to affect the bowel.</p> <p>The symptoms of DLBCL depend on what part of the body is involved. Some people have no symptoms other than a lump or swelling. Others experience weight loss, flu-like symptoms or night</p>

	<p>sweats. It is quite common for DLBCL to cause gastric symptoms such as abdominal pain.</p>
<p>How is it treated?</p>	<p>DLBCL is treated with a combination of chemotherapy and antibody therapy. The most commonly used treatment is R-CHOP.</p> <p>CHOP stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You don't usually need to stay in hospital to have this treatment.</p> <p>The 'R' stands for an antibody therapy called rituximab. Rituximab or MabThera® targets a protein called CD20, which is found on the surface of most B-cells. It then helps your immune system to kill the malignant B-cell. Rituximab is given through a drip. Sometimes people stay in hospital overnight after their first dose of rituximab.</p> <p>A small proportion of people with DLBCL do not produce CD20 on their B-cells. These people will have treatment with CHOP alone.</p> <p>Some people with DLBCL will have treatment with radiotherapy as well as chemotherapy.</p> <p>This includes people who have early stage disease – Stage 1A or 2A. In these cases, chemotherapy may be reduced to a period of 2 – 3 months.</p> <p>It also includes people who had a particularly large tumour to start with. This large tumour may be</p>

treated with radiotherapy once chemotherapy has finished.

Some people with DLBCL may need treatment to the brain and spinal cord, or central nervous system, to prevent the lymphoma spreading there. The central nervous system is more difficult to treat than other parts of your body. To give it the best treatment possible, chemotherapy has to be given directly into your cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. Intrathecal chemotherapy is given through an injection into your back called a lumbar puncture.

You will find these treatments discussed in more detail on pages 53-59
.....▶

Adult T-cell leukaemia / lymphoma

T-cell or B-cell?	T-cell
What does it mean?	<p>Adult T-cell leukaemia / lymphoma (ATLL) is a rare peripheral T-cell lymphoma.</p> <p>ATLL is closely related to acute leukaemia. Both are diseases of immature blood cells. In theory, lymphoma is a disease that forms lumps in the lymphatic system, and leukaemia is a disease that grows in the bone marrow and the blood. In practice, the two diseases often do the same things as each other. Like leukaemia, ATLL can result in lots of malignant T-cells in the bone marrow and in the blood.</p>
Who gets it?	<p>In most cases of lymphoma, the cause is unknown. But scientists now know that ATLL is associated with a particular virus called HTLV I. ATLL is more common in those parts of the world where more people carry HTLV I. This is particularly the case in Japan, but also in South East Asia, the Caribbean, South Eastern USA and equatorial Africa. It is much less common in the UK.</p>

	<p>ATLL is more common in Asian or Afro-Caribbean people. The majority of cases occur in those aged 50 – 60.</p>
<p>How will it affect me?</p>	<p>The symptoms are varied. Some patients may have no symptoms. Some just notice a lump. In others, there is a rapid onset of symptoms such as enlargement of lymph nodes, night sweats and fevers.</p> <p>ATLL very commonly involves the bone marrow. This can cause a failure in the production of healthy blood cells, resulting in anaemia and bleeding.</p> <p>ATLL commonly causes high levels of calcium in the blood. This is called hypercalcaemia. This can result from disease in the bone. It can also happen as a result of abnormal hormone and enzyme production in response to the malignant T-cells.</p> <p>ATLL causes enlarged lymph glands, enlarged liver and spleen. It commonly involves the skin causing widespread reddened itchy patches.</p> <p>ATLL is more likely to affect the brain and spinal cord, or central nervous system (CNS).</p>
<p>How is it treated?</p>	<p>In some cases, people who feel well will be observed without treatment.</p> <p>Treatments for ATLL will vary depending on the individual situation.</p> <p>The most common treatment is chemotherapy. The chemotherapy used is CHOP. 'CHOP' stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. It is given over a course</p>

of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You don't need to stay in hospital to have this treatment.

Anti-retroviral treatments may be given on their own or in addition to chemotherapy. This is to help fight the HTLVI virus. These drugs include interferon, AZT and Combivir.

Anaplastic large T-cell lymphoma

T-cell or B-cell?	T-cell
What does it mean?	<p>Anaplastic large T-cell lymphoma (ALTCL) is a sub-type of peripheral T-cell lymphoma (see page 48). The word 'anaplastic' means disordered growth.</p> <p>You may recall when we talked about classification that we mentioned changes in the genes (DNA) in the nucleus of the cell. ALTCL has a typical change in the cell DNA that makes it distinct from other lymphomas. The cause of this change is unknown. Unregulated growth occurs because of the change in the cell genes.</p> <p>In some cases, this gene change creates a protein called ALK (anaplastic large cell kinase). You may hear your doctor refer to 'ALK positive' or 'ALK negative'.</p> <p>In most cases of ALTCL a particular cell can be seen under the microscope with a bean shaped nucleus. You may hear this referred to as a 'hallmark cell'.</p>

Who gets it?	<p>ALTCL makes up around 2% of all non-Hodgkin lymphomas. It tends to affect younger adults.</p>	
How will it affect me?	<p>The most common symptom of ALTCL is enlarged lymph nodes. You may also experience other symptoms of lymphoma including fevers and weight loss.</p> <p>ALTCL can involve other organs of the body. It can involve tissues that are not commonly affected by lymphoma, such as the bone.</p> <p>Like other T-cell lymphomas, ALTCL can involve the skin. In some cases, it will be confined to the skin alone. When it involves the skin, it causes patches that are reddened, itchy, raised and scaly.</p>	
How is it treated?	<p>ALTCL is treated with chemotherapy. This treatment is abbreviated to CHOP.</p> <p>‘CHOP’ stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You don’t need to stay in hospital for this treatment.</p> <p>You may have read on other pages about an antibody treatment called rituximab. Rituximab is used for some kinds of B-cell lymphoma. It is not used for ALTCL.</p> <p>People who have particularly large lymph nodes may also be offered treatment with radiotherapy to the larger nodes.</p> <p>ALK negative ALTCL confined to the skin may get better without treatment.</p>	<p><i>You will find these treatments discussed in more detail on pages 53-65</i></p> <p>.....▶</p>

Angioimmunoblastic lymphoma (AIL)

T-cell or B-cell?	T-cell
What does it mean?	<p>Angioimmunoblastic lymphoma (AIL) is a rare T-cell non-Hodgkin lymphoma.</p> <p>The term 'angio' refers to blood vessels. The tumours of AIL are marked by the growth of abnormal blood vessels, and the overgrowth of a range of different immature cells, or 'blast' cells.</p>
Who gets it?	AIL makes up around 1% of non-Hodgkin lymphomas. It is more common in those aged over 60. It affects more men than women.
How will it affect me?	<p>AIL can produce a wide range of symptoms.</p> <p>It produces widespread enlargement of lymph nodes and commonly involves the liver and the spleen. People with AIL also tend to experience the other symptoms of lymphoma, especially fevers, itching weight loss and night sweats.</p> <p>It can produce effects such as skin rashes, inflammation of the joints, pins and needles and numbness. These symptoms are often 'auto-immune'. In other words, your body is having an immune reaction to its own tissue. It is thought that the malignant T-cells produce abnormal proteins, and these proteins cause the autoimmune reaction.</p>
How is it treated?	<p>AIL is difficult to treat successfully.</p> <p>The usual first treatment is chemotherapy. The chemotherapy used is CHOP. 'CHOP' stands for a combination of chemotherapy drugs:</p>

Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets.

You don't need to stay in hospital to have this treatment.

You may have read on other pages about an antibody treatment called rituximab. Rituximab is used for some kinds of B-cell lymphoma. It is not used for ALL.

Although many people will have a response to CHOP, it is common for ALL to come back, or 'relapse'. In these cases, other types of chemotherapy may be offered. Some people may be offered treatment with a stem cell or bone marrow transplant.

In some cases, in particular in cases where the person is not well enough for chemotherapy, steroids will be used to try and control the disease and improve symptoms.

Other treatments have been tested for ALL. These include thalidomide. It is thought that thalidomide might help cancers die by preventing them from growing the blood vessels they need to survive. This treatment is still in its early stages.

You will find more about these treatments on pages 53-65



Burkitt's lymphoma

T-cell or B-cell?	B-cell
What does it mean?	Burkitt's lymphoma (BL) is named after a doctor by the name of Burkitt, who first wrote about this kind of lymphoma in young children from parts of Africa.

	<p>Sometimes pathologists use the words ‘small non-cleaved’, or ‘starry sky’ when talking about the cells of BL. These terms refer to what the cells look like under the microscope.</p> <p>You may hear doctors refer to ‘Burkitt-like’ or ‘atypical Burkitts lymphoma’. These are very similar to BL and are treated in the same way.</p> <p>The exact cause of BL is not known. But doctors do know that it happens because of changes to the DNA (genes) of the cell. These genetic changes lead to uncontrolled cell growth.</p>
Who gets it?	<p>BL affects both children and adults.</p> <p>The average age of adults with BL is 30. It affects men more than women.</p> <p>BL is more common in people who have HIV or AIDS. These lymphomas happen partly because of the HIV virus and other viruses including Epstein-Barr Virus (EBV). EBV causes prolonged stimulation of B-cells, which seems to increase the chances of the cells becoming malignant.</p>
How will it affect me?	<p>BL causes widespread enlargement of lymph nodes in different parts of the body, including the chest, the tonsils and the back of the nose and throat. You may also experience the other symptoms of lymphoma, including night sweats, tiredness, flu like symptoms and unexplained weight loss.</p> <p>BL commonly affects the bowel and the lymph nodes in the abdomen. People with BL very often go to the doctor with abdominal pain, nausea, vomiting and diarrhoea. The symptoms of BL often resemble something like appendicitis. It can</p>

cause a collection of fluid within your abdomen – this is called ‘ascites’. It can also cause obstruction of the bowel or bleeding in the bowel.

BL can also be found in other organs such as the spleen and the liver. Many people with BL will have disease in their bone marrow at the time they first see the doctor.

BL is more likely to involve the brain and spinal cord than other lymphomas.

BL grows very quickly. The symptoms can develop in a short space of time.

BL in children often affects the jaw. The disease commonly grows in the areas where permanent teeth are forming.

How is it treated?

Because BL grows so quickly, it is important that treatment begins as soon as possible.

BL is treated with combination of chemotherapy drugs. Commonly used combinations include CODOX-M or CODOX-M combined with IVAC. These initials refer to the names of the individual drugs. The staff at your hospital will give you information about the drugs you are having.

CODOX-M on its own is used for people with disease that is at an early stage and disease that has not yet had a big impact on general health.

CODOX-M / IVAC is used for people with more advanced disease who are more seriously ill at the time of treatment.

In some cases, rituximab is added to chemotherapy for BL. Rituximab or MabThera® targets a protein

called CD20, which is found on the surface of most B-cells. It helps your immune system to kill the malignant B-cell. Rituximab is given through a drip.

You will also be given other drugs at the same time to prevent or lessen the side effects of the chemotherapy drugs.

These drugs are given over a period of 2 weeks or so. In the case of CODOX-M / IVAC the groups of drugs are given alternately. The cycle is then repeated 2 or 3 times. It takes 3 – 4 months. You will have to stay in hospital for some of this period.

Burkitt's lymphoma can involve the brain and spinal cord, known as the central nervous system or CNS. Even if you don't have BL in your CNS, your doctors will treat it to prevent the lymphoma spreading there.

The central nervous system is more difficult to treat than other parts of your body. To give it the best treatment possible, chemotherapy has to be given directly into your cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. Intrathecal chemotherapy is given through an injection into your back called a lumbar puncture.

You will find more about intrathecal chemotherapy on pages 55-56
.....▶

In people who have HIV or AIDS, the treatment of Burkitt's lymphoma may be different. This will depend on things such as how well you are and what your T-cell count is.

Treatment of lymphoma in those with HIV or AIDS is discussed on pages 36-38
.....▶

CODOX-M and IVAC are intensive chemotherapy treatments, with severe potential side effects. Some people may be too frail or unwell to cope with the side effects. These people may receive treatment with CHOP chemotherapy.

Enteropathy associated T-cell lymphoma (Intestinal T-cell lymphoma)

T-cell or B-cell?	T-cell
What does it mean?	<p>Enteropathy associated T-cell lymphoma (EATCL) occurs in the small bowel. 'Enteropathy' means degeneration or wasting of the small bowel.</p> <p>EATCL is an extranodal type of peripheral T-cell lymphoma. Extranodal means that it starts growing outside of the lymphatic system.</p> <p>EATCL is often associated with coeliac disease. Coeliac disease is a condition in which the person's small bowel is unable to digest a protein called gluten. EATCL is usually associated with coeliac disease that begins in adulthood and not coeliac disease that begins in childhood. Sometimes the coeliac disease is found at the same time as the lymphoma.</p> <p>EATCL can also occur on its own, without the presence of coeliac disease.</p> <p>EATCL can be hard to diagnose because it is difficult to get good-enough pictures of the bowel using standard types of scan.</p>
How will it affect me?	<p>Most people with EATCL go to their doctor with bowel and stomach problems, in particular diarrhoea, abdominal pain and unexplained weight loss.</p> <p>EATCL can also cause enlargement of lymph nodes in the abdomen and other parts of the body. You may experience night sweats and fevers.</p>

How is it treated?

The usual treatment for EATCL is CHOP chemotherapy.

‘CHOP’ stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets.

You don’t need to stay in hospital to have this treatment.

EATCL can be difficult to treat successfully. You may be offered other kinds of chemotherapy if CHOP fails to produce a response.

Some specialists feel that more intensive chemotherapy treatments, perhaps including stem cell transplant, might be useful for people with EATCL.

In some cases, it is necessary to perform surgery to remove the affected parts of the bowel. This is not considered to be sufficient treatment on its own, as the lymphoma would have a good chance of coming back in other areas. Surgery is usually carried out before chemotherapy.

You may have read on other pages about an antibody treatment called rituximab. Rituximab is used for some kinds of B-cell lymphoma. It is not used for EATCL.

HIV and AIDS related lymphoma

T-cell or B-cell?	Usually B-cell.
What does it mean?	<p>Lymphomas are more common in people who have something wrong with their immune system. This is particularly the case for people who have HIV or AIDS.</p> <p>There are different kinds of lymphomas that affect people with HIV and AIDS. These lymphomas are usually high grade and grow from B-cells, most commonly diffuse large B-cell lymphoma and Burkitt's lymphoma.</p> <p>Other people with HIV / AIDS will develop lymphoma that starts in, and is confined to, the brain and spinal cord. This is known as Primary Central Nervous System Lymphoma (PCNSL).</p> <p>Lymphoma in HIV / AIDS seems to result from the prolonged over-stimulation of B-cells. This may happen as a result of the presence of viruses.</p>
Who gets it?	<p>Although people with HIV alone can develop non-Hodgkin lymphoma, it is more common in people who have AIDS. The longer you have had HIV or AIDS, the greater your chance of developing lymphoma.</p> <p>You are more likely to develop lymphoma if you have experienced previous AIDS-defining illnesses, in particular Kaposi's sarcoma.</p>
How will it affect me?	<p>How your lymphoma affects you depends on what kind of lymphoma it is. The most common symptom of lymphoma is a painless lump or swelling in the neck, armpit or groin. Other symptoms include drenching night sweats, fevers, unexplained weight loss and diarrhoea.</p>

For more information about the effects of individual lymphomas, turn to other pages of this booklet dealing with these lymphomas in particular.

How is it treated?

HIV/AIDS related lymphoma is more difficult to treat than lymphomas in people who do not have HIV.

What treatment you have will depend on what kind of lymphoma you have. It will also depend on your CD4 count, and whether you are well enough to cope with the side effects of chemotherapy. For example, those with a CD4 count of 100 cells/mm³ or less might cope better with chemotherapy at a reduced dose.

Primary Central Nervous System Lymphoma is usually treated with chemotherapy, sometimes in combination with radiotherapy. It is also treated with steroids such as Dexamethasone, to reduce the swelling in the brain. This illness is very difficult to treat successfully. Treatment may not prolong survival but is aimed to reduce symptoms and improve quality of life.

Other lymphomas will be treated with combinations of intravenous chemotherapy.

If you have Burkitt's lymphoma you may be treated with CODOX-M / IVAC. You will find treatment of Burkitt's described on pages 30-32.

Many high grade non-Hodgkin lymphomas are treated with chemotherapy called CHOP. 'CHOP' stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given

in a drip and some that are taken as tablets. You don't need to stay in hospital to have this treatment.

Occasionally an antibody therapy called rituximab is added to chemotherapy. Rituximab or MabThera® targets a protein called CD20, which is found on the surface of most B-cells. It helps your immune system to kill the malignant B-cell. The use of Rituximab in people with HIV / AIDS can cause problems. In someone with an already damaged immune system, the use of rituximab can significantly increase the risk of infection because of damage to healthy B-cells.

Some lymphomas that occur in people with HIV or AIDS can involve the brain and spinal cord (CNS). Your doctor may wish to treat your CNS to prevent disease spreading there.

The CNS is more difficult to treat than other parts of the body. In order to give it the best treatment possible, chemotherapy is given directly into your cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. It is given through an injection into your back called a lumbar puncture.

Other drugs will be given together with chemotherapy to help protect you from infection. In some cases, the dose of chemotherapy may have to be modified to take account of low CD4 counts.

If you are taking HAART, the current recommendation is to continue taking HAART with chemotherapy. It is important to continue to take PCP preventative medicines during chemotherapy.

Intestinal T-cell lymphoma

See 'Enteropathy associated T-cell lymphoma' on page 34.

Lennerts lymphoma

In the past, classification systems used to refer to a rare peripheral T-cell lymphoma called Lennerts Lymphoma. This term is still used sometimes, but it is now more often described as peripheral T-cell lymphoma. If you have Lennert's lymphoma, the information on peripheral T-cell lymphoma on pages 48-49 will be relevant to you.

Lymphoblastic lymphoma

T-cell or B-cell?	Most cases of lymphoblastic lymphoma are T-cell. Some cases are B-cell.
What does it mean?	<p>Most lymphomas grow from mature lymphocytes – that is, lymphocytes that are fully developed before they become malignant.</p> <p>Lymphoblastic lymphoma grows from an immature lymphocyte – a lymphocyte that is at an early stage of development. A 'lymphoblast' is an immature lymphocyte. They are also called blasT-cells.</p> <p>Lymphoblastic lymphomas are closely related to acute leukaemia. Both are diseases of immature blood cells. In theory, lymphoma is a disease that forms lumps in the lymphatic system, and leukaemia is a disease that grows in the bone marrow and the blood. In practice, the two diseases often do the same things as each other. Like leukaemia, lymphoblastic lymphoma can result in lots of immature cells in the bone marrow and in the blood.</p>

	<p>Lymphoblastic lymphoma grows from immature B and T-cells. T-cell lymphoblastic lymphoma is more common than B-cell lymphoblastic lymphoma.</p>
<p>Who gets it?</p>	<p>Lymphoblastic lymphoma affects young people, typically those in their late teens or twenties. It is more common in men than women.</p>
<p>How will it affect me?</p>	<p>Lymphoblastic lymphoma very often causes a large tumour in the lymph nodes of the mediastinum. The mediastinum is the area of the chest between the lungs. It contains the heart, the wind pipe, the oesophagus (where food goes down) and other structures including the major blood vessels and the thymus gland, where T-cells mature.</p> <p>Enlarged mediastinal nodes can cause a cough, shortness of breath, and problems with your circulation. Large chest nodes can often be seen when you have a chest x-ray.</p> <p>Lymphoblastic lymphoma can also cause problems with the layers surrounding your lungs – the pleura. This can cause pain in your chest when you breathe. It sometimes causes a collection of fluid around your lung, known as a pleural effusion.</p> <p>You may also experience the other symptoms of lymphoma, including night sweats, tiredness, flu like symptoms and unexplained weight loss.</p> <p>Because of the similarity with leukaemia, you may experience problems with your bone marrow. The production of immature cells in the marrow can prevent it from making healthy blood cells. This can result in anaemia, which causes shortness of breath, bone pain and fatigue. Bone marrow disease can also make you more prone to infections and bleeding.</p>

Lymphoblastic lymphoma can involve the brain and spinal cord.

Lymphoblastic lymphoma grows very quickly. You may find that your symptoms develop within a short space of time.

How is it treated?

Because this illness grows very quickly, it is important that treatment begins as soon as possible.

Lymphoblastic lymphoma is treated with the same kind of chemotherapy used for acute leukaemia.

This treatment takes much longer than most lymphoma treatments. It is divided into different phases.

The first phase is called 'remission induction'. This means that the treatment aims to get the lymphoma to a stage where it can no longer be easily detected. Remission induction means having a number of different chemotherapy drugs in a drip and as tablets. This happens over a period of several weeks. The exact duration will depend on the drug combination you are having. You will have to stay in hospital for this time.

The next phase is called 'consolidation'. The aim of this phase is to kill off any lymphoma cells that are still floating around but that can't be detected easily. Consolidation involves more chemotherapy drugs given over a period of a few months. You usually don't have to stay in hospital during this time.

The third phase of treatment is called 'maintenance'. This involves taking chemotherapy

You will find more about these treatments on pages 53-65



tablets and sometimes having chemotherapy through a drip for a period of two years.

Lymphoblastic lymphoma can involve the brain and spinal cord, known as the central nervous system or CNS. Even if you don't have lymphoma in your CNS, your doctors will treat it to prevent the lymphoma spreading there.

The central nervous system is more difficult to treat than other parts of your body. In order to give it the best treatment possible, chemotherapy is given directly into your cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. Intrathecal chemotherapy is given through an injection into your back called a lumbar puncture.

Some people may be offered a stem cell transplant when they are in remission. This depends on your individual situation.

Mantle cell lymphoma

T-cell or B-cell?

B-cell.

What does it mean?

Mantle cell lymphoma (MCL) is an uncommon type of non-Hodgkin lymphoma. Doctors sometimes describe MCL as a low grade lymphoma that behaves in an aggressive or high grade way. This can sound a bit confusing. Although the appearance of MCL makes it look low grade, it is treated as a high grade illness.

The word 'mantle' is used because the lymphoma cells arise from a part of the lymph node called the mantle zone.

<p>Who gets it?</p>	<p>MCL makes up about 5% of all non-Hodgkin lymphomas. It is more common in men than in women. It is more likely to affect older people. The average age at which MCL is diagnosed is 65.</p> <p>The exact cause of MCL is not known. Doctors do know that it happens because of changes to the DNA (genes) of the cell. As a result of these changes, the cell produces too much of a particular protein. Too much of this protein results in uncontrolled cell growth. This leads to the development of the lymphoma.</p>
<p>How will it affect me?</p>	<p>Most people with MCL go to their doctor with enlarged lymph glands.</p> <p>Most people with MCL will have advanced disease – stage 3 or 4 – by the time it is diagnosed. The bone marrow is usually involved. Sometimes lymphoma cells can be found in the blood stream.</p> <p>It is very common for MCL to involve the bowel. This means that people with MCL can experience symptoms like diarrhoea and abdominal pain.</p> <p>Some people will have a variant of MCL called ‘blastic’ mantle cell lymphoma. The word ‘blastic’ refers to a very immature lymphocyte. Blastic MCL grows very quickly.</p>
<p>How is it treated?</p>	<p>MCL is difficult to treat successfully. It is less responsive to chemotherapy than other lymphomas. It is not considered to be curable. Most doctors will aim to get the disease into as good a remission as possible for as long as possible.</p> <p>The treatment of MCL varies according to individual circumstances.</p>

Some people who feel relatively well will have no treatment until their symptoms become more difficult to live with.

Sometimes people will have treatment with tablet chemotherapy such as chlorambucil or cyclophosphamide.

Some people will have treatment with a kind of chemotherapy called CHOP. 'CHOP' stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You don't have to stay in hospital for this treatment.

Although CHOP is used in lots of cases of lymphoma, it does not work as well for MCL. For this reason, your doctor may suggest another combination of chemotherapy drugs. The staff at your hospital will give you information about the drugs you are having. Some combinations of chemotherapy have more severe side effects, and may require admission to hospital.

It is common for doctors to add rituximab to chemotherapy for the treatment of MCL. Rituximab or MabThera[®] targets a protein called CD20, which is found on the surface of most B-cells. It then helps your immune system to kill the malignant B-cell. Rituximab is given through a drip. Sometimes people stay in hospital overnight following their first dose of rituximab.

Sometimes more intensive treatment is used for MCL. These treatments are used for those who are relatively young and in good general health.



For more information about mantle cell lymphoma, please telephone the helpline for a copy of our fact file

This is because intensive treatments have worse side effects, and not all people can cope with them. These treatments include stem cell and bone marrow transplants.

Trials are planned to test different types of treatment for MCL. These are drugs that have had some activity in other cancers and may be useful for MCL. They include thalidomide and Velcade. These trials are reserved for people who have already had chemotherapy.

Mediastinal diffuse large B-cell lymphoma

T-cell or B-cell?	B-cell
What does it mean?	Mediastinal diffuse large B-cell lymphoma (MDLBCL) particularly involves the lymph nodes in the mediastinum. The mediastinum is the area of the chest between the lungs. It contains the heart, the wind pipe, the oesophagus (where food goes down) and other structures including lymph nodes and major blood vessels.
Who gets it?	MDLBCL affects younger people usually aged in the 20's – 30's. It is twice as common in women as it is in men.
How will it affect me?	<p>MDLBCL is quite often confined to the chest area – or localised – at the time of diagnosis.</p> <p>The enlargement of the chest lymph nodes can cause a cough, shortness of breath and difficulty breathing.</p> <p>You may also experience the other symptoms of lymphoma, including fever, night sweats and weight loss.</p>

How is it treated?

MDLBCL is treated with a combination of chemotherapy and antibody therapy. The most commonly used treatment is R-CHOP.

'CHOP' stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You don't usually need to stay in hospital to have this treatment.

The 'R' stands for an antibody therapy called rituximab. Rituximab or MabThera® targets a protein called CD20, which is found on the surface of most B-cells. It then helps your immune system to kill the malignant B-cell. Rituximab is given through a drip. Sometimes people stay in hospital overnight after their first dose of rituximab.

A small proportion of people with DLBCL do not produce CD20 on their B-cells. These people will have treatment with CHOP alone.

You may have treatment with radiotherapy. Radiotherapy is given to the enlarged lymph nodes in your chest.

Nasal type T – cell lymphoma

T-cell or B-cell?	Most nasal type lymphomas are T-cell. Some are B-cell.
What does it mean?	Nasal T-cell lymphoma is an ‘extranodal’ subtype of peripheral T-cell lymphoma. Extranodal means that it starts growing outside of the lymphatic system. In this case, it starts to grow in the sinuses, which are the tubes surrounding your nasal passages.
How will it affect me?	<p>Nasal lymphomas are often diagnosed at stage I or 2. In other words, they are confined to the area around your nose. You may hear this referred to as Stage I or 2E, where the E stands for ‘extranodal’.</p> <p>Common symptoms of nasal lymphoma include a blocked nose, discharge or bleeding from the nose, weepy eyes, swelling in the face or dental problems.</p> <p>Some nasal lymphomas seem to be connected to the Epstein Barr virus. It is thought that the virus may in some way increase the chances of malignant changes to the normal cells.</p>
How is it treated?	<p>Nasal T-cell lymphoma is treated with a combination of radiotherapy and chemotherapy.</p> <p>Radiotherapy will be given to the areas affected by the lymphoma.</p> <p>Chemotherapy is used even if the disease seems to be confined to the nasal area. This is because lymphoma can often come back in places outside the area treated with radiotherapy. Chemotherapy</p>

treats the cells that might be lurking elsewhere but which are difficult to detect.

The chemotherapy treatment is CHOP.

‘CHOP’ stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets.

You don’t need to stay in hospital to have this treatment.

Peripheral T-cell lymphoma

T-cell or B-cell?	T-cell
What does it mean?	This term refers to a group of similar lymphomas that all arise from T-cells that start in the lymphatic system. The word ‘peripheral’ means that the T-cells mature in parts of the body peripheral to – or outside of – the thymus.
Who gets it?	Peripheral T-cell lymphoma makes up around 7 – 8% of all non-Hodgkin lymphomas. It is a disease that occurs in adulthood, more often in those aged over 50. It affects more men than women.
How will it affect me?	<p>Most people will have advanced disease at stage III or IV by the time they go to the doctor.</p> <p>Most people with peripheral T-cell lymphoma go to the doctor with relatively small enlarged lymph nodes in widespread parts of the body. You may</p>

also experience night sweats, fevers and unexplained weight loss.

Peripheral T-cell lymphoma can also cause enlargement of the liver and the spleen. It often affects the bone marrow.

Peripheral T-cell lymphoma can affect the skin, causing reddened, itchy patches.

How is it treated?

Peripheral T-cell lymphoma is treated with chemotherapy. This treatment is called CHOP.

'CHOP' stands for a combination of chemotherapy drugs: Cyclophosphamide, Hydroxydaunorubicin, Oncovin, Prednisolone. This combination of drugs has been used for many years in the treatment of high grade non-Hodgkin lymphoma. It is given over a course of 4-6 months, and includes some drugs that are given in a drip and some that are taken as tablets. You usually don't need to stay in hospital to have this treatment.

Peripheral T-cell lymphoma can be difficult to treat successfully. If your disease does not respond to CHOP, you may be offered other kinds of chemotherapy.

You may have read on other pages about an antibody treatment called rituximab. Rituximab is added to CHOP chemotherapy for some kinds of B-cell lymphoma. It is not used for peripheral T-cell lymphoma.

People who have particularly large lymph nodes may also be offered treatment with radiotherapy to the larger nodes.

Primary central nervous system lymphoma

T-cell or B-cell?	Usually B-cell
What does it mean?	<p>Non-Hodgkin lymphomas can affect almost any part of the body, including the brain and spinal cord, or central nervous system (CNS). Lymphoma can press on the CNS from outside it, or it can spread to within the CNS from some other part of the body.</p> <p>Primary central nervous system lymphoma (PCNSL) is a lymphoma that starts within the central nervous system.</p>
Who gets it?	<p>PCNSL is a very rare condition that affects men more than women. It is more common in those aged in their 50's or 60's. It is more common in people who have a suppressed immune system, such as those who have HIV or AIDS.</p>
How will it affect me?	<p>PCNSL can affect a person in many different ways, depending on what part of the CNS is involved. The effects will also depend on whether the lymphoma is a mass that is pressing on part of the CNS, or whether it causes inflammation of the layers that surround the CNS, called the meninges.</p> <p>Possible symptoms of PCNSL include headaches, changes in vision, drowsiness, problems with balance, seizure, muscle weakness, change in personality or difficulty expressing oneself.</p> <p>You will have an MRI in addition to the tests described on pages 11-15. MRI is particularly good at providing pictures of nerve tissue.</p> <p>Your specialist may advise a biopsy of lymphoma</p>

For more information about tumours of the brain, you can contact the British Brain and Spinal Cord Foundation on 0808 808 1000

The Lymphoma Association produces a fact file about lymphomas in the central nervous system. Please telephone our helpline for a copy

in the CNS. This is because other types of brain tumour are treated differently from PCNSL. It is important to find out what kind of cancer is there before deciding on treatment. A biopsy will involve an operation to get into the area of the CNS involved and take a sample of tissue.

How is it treated?

PCNSL is a difficult disease to treat successfully. People with PCNSL are often very sick by the time the lymphoma is found.

Treatment will be planned on an individual basis.

Most people will have treatment with steroids, such as dexamethasone, which is given through a drip. The steroids are given to reduce the size of the tumour and reduce swelling in the diseased area. This can help to alleviate symptoms. Steroids are not usually sufficient to cure the lymphoma.

Other treatments include chemotherapy. The central nervous system is more difficult to treat than other parts of your body. This is because the CNS is protected by something called the blood – brain barrier. The blood brain barrier protects the CNS from invasion by infection, and also prevents drugs from getting in. Some drugs can get through the blood brain barrier from your blood stream. Other drugs have to be given directly into your cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. Intrathecal chemotherapy is given through an injection into your back called a lumbar puncture.

Radiotherapy is also commonly used for PCNSL, particularly if the disease is confined to one area. It can be difficult to treat with radiotherapy if the disease is widespread throughout the CNS.

Summary

- Diffuse large B-cell lymphoma is the most common type of high grade non-Hodgkin lymphoma.
- High grade non-Hodgkin lymphomas can be quite different from one another.
- Some, such as Burkitt's and Lymphoblastic lymphoma, grow very quickly. Others, such as mantle cell lymphoma, grow more slowly.
- High grade non-Hodgkin lymphoma can affect lots of different parts of the body.
- The treatment you have will depend on what kind of lymphoma you have, and what parts of your body are likely to be affected by the lymphoma.
- Most high grade non-Hodgkin lymphomas will be treated with chemotherapy.
- Some people will have chemotherapy given directly to the central nervous system.
- Other treatments include antibody therapies, radiotherapy to the affected lymph nodes and stem cell transplant.

The next section of the booklet will discuss treatment in more detail, including side effects of treatment and how to deal with them.

Part Three:

Treatment of high grade non-Hodgkin lymphoma

3

Treatment for high grade non-Hodgkin lymphoma differs from person to person. The staff at the hospital should give you information about your treatment in particular.

This part of the booklet discusses:

Chemotherapy

Radiotherapy

Antibody therapy

Stem cell transplants

Side effects

Your treatment hospital

What happens after treatment

About chemotherapy

This section will discuss

what chemotherapy is

how chemotherapy is given

What is chemotherapy?

The word chemotherapy literally means treatment with drugs. Drugs for cancer are called cytotoxic drugs because they kill cells: 'cyto' means cell, and 'toxic' means poisonous.

Chemotherapy works by interrupting the reproductive cycle of the lymphoma cell. Different chemotherapy drugs do this in different ways. Chemotherapy drugs particularly target T-cells that divide quickly.

Chemotherapy for lymphoma usually involves giving more than one kind of drug. This increases the chances of killing as many cancer cells as possible. These drugs are given through a drip and in tablets.

How chemotherapy is given

Chemotherapy for high grade non-Hodgkin lymphoma is given over a period of several months. You will have treatment some weeks with rest periods in between. The exact timetable for your treatment will depend on what kind of chemotherapy you are having. You will be given information about your treatment and what side effects to expect.

Chemotherapy for high grade lymphoma may be given as an outpatient. This means you will visit hospital on the day of treatment but go home afterwards. Some types of chemotherapy will be given as an inpatient. This means you will need to stay in hospital. Your specialist will discuss this with you when you are planning your treatment.

Some chemotherapy is given as a tablet. You will be told what to take and what time of day to take it. Most chemotherapy is given intravenously. This means through a tube into a vein. In some cases, chemotherapy is given intrathecally. This means into the fluid that surrounds your brain and spinal cord.

Intravenous chemotherapy

Intravenous drugs are delivered through a small tube that is put into one of your veins. The nurse or doctor will often use a vein on the back of your hand or in your lower arm. A needle is put in first, and then taken out, leaving a soft tube resting in the vein. This is secured with adhesive to keep it in position. Usually, this tube will be taken out before you go home and another one put in next time.

Some intravenous drugs are given as a 'bolus' or a 'push' dose. This means that the nurse injects the drug into the tube all at once.

Other intravenous drugs are given as an 'infusion', or a drip. They are mixed with another fluid in a bag, and the bag is set up to drip into the tube in your arm over a period of time. The bag of fluid needs to be kept higher than your arm, and it will usually be hung on a pole. The poles are often mobile, so you can walk around while the drip is connected. You might have more than one bag going at the same time. You might need to go to the toilet more often.

Drugs are often given using machines that regulate the flow of liquid. They are boxes that attach to the pole, and the intravenous tube is fed through them. They can 'beep' from time to time if something is not right. This might sound alarming at the time, but don't worry. The flow of fluid stops until the problem is sorted out.

It is common for people to have intravenous chemotherapy through a central line. A central line is a more permanent intravenous tube. This makes it easier to give drugs and take blood samples, without the discomfort of repeated needles. A central line goes into a vein further inside your body. They are usually positioned on your upper chest, just below your shoulder. The position of the drip needs to be checked on an x-ray.

The central line stays in for the duration of your treatment, and will be covered to protect it when you go home. You will be given instructions about how to care for your central line.

Intrathecal chemotherapy

Some kinds of high grade non-Hodgkin lymphoma may involve the brain and spinal cord, or central nervous system (CNS). The CNS is surrounded by a fluid called cerebrospinal fluid, or CSF.

The central nervous system is protected by something called the 'blood / brain barrier'. Some drugs can cross the blood / brain barrier, but most chemotherapy drugs cannot. To treat your central nervous system it may be necessary to give chemotherapy directly into the CSF. This way of giving chemotherapy is called intrathecal chemotherapy.

Intrathecal chemotherapy is given using a procedure called a lumbar puncture. It is given by a senior doctor who is specially qualified to give intrathecal chemotherapy. The doctor will put a needle between two of the bones in the lumbar part of your spine, or the small of your back. You will be positioned either on your side curled up with your knees to your chest, or sitting up and leaning forward onto a support. The doctor will give the chemotherapy drug through the needle. This will take place in a different room to your usual chemotherapy.

You will be asked to lie very still. You may have to lie down for a period of time afterwards.

Steroids

The word 'steroid' refers to a large family of similar drugs. They are all drugs that imitate hormones produced naturally by the body. The steroids used in lymphoma treatment help to kill the lymphoma cells. They also reduce nausea and help you to feel better. Steroids are given as tablets.



The Lymphoma Association produces a fact file about lymphomas in the central nervous system. Please telephone our helpline for a copy

Summary

- Chemotherapy usually lasts several months.
- Chemotherapy may be given as an outpatient, which means you don't have to stay in hospital. In some cases, it will be given as an inpatient. This means that hospital admission will be necessary.
- Chemotherapy for high grade non-Hodgkin lymphoma uses a combination of drugs.
- Chemotherapy can be given as a tablet, into a vein (intravenous) or into the CSF (intrathecal).
- You may have a central line put in for your chemotherapy. This is like a semi-permanent drip.
- You may have steroids as part of your chemotherapy.
- You will be given information about the side effects to expect and what to look out for.

About radiotherapy

This section will discuss

what radiotherapy is

how radiotherapy is given

What is radiotherapy?

Radiotherapy uses high energy rays directed through the enlarged lymph nodes. These rays are similar to the rays used when taking an X-ray, but they are delivered in much higher doses. The rays stop the cells from dividing and kill them.

Radiotherapy is used for some people with high grade non-Hodgkin lymphoma. It may be used as a treatment on its own for early stage disease. It is more often used in combination with chemotherapy.

How radiotherapy is given

Radiotherapy is usually given daily Monday to Friday, and you will be able to go home after each treatment. Treatment usually takes 4-6 weeks.

A radiotherapy department can feel like quite a high-tech and impersonal environment, with big machines and no windows. It can be unnerving at first, particularly as you will be left alone for some of the time.

The first stage of treatment is planning. This may involve more than one visit to the department before treatment starts. Using a machine called a 'simulator', radiographers will take several x-rays of the area to be treated. A computer then produces a treatment plan that is particular to you.

The radiographer will mark your skin with a marker pen. These marks need to remain visible throughout treatment.

During treatment, you will be carefully positioned on a narrow table and asked to stay very still. The radiographer may cover certain parts of your body that do not need treatment. The lights in the radiation room are dimmed while you are getting into position. This is so that the team can see the beams of light that are used to line up the machine. The lights will then be turned back up.

You will be left alone for the time it takes to give the treatment. The radiographer will be watching from a room next door. You will be able to hear what they say and they can hear you. The room may have a CD player, so you can take along some music to listen to.

The length of time treatment takes will depend on your individual situation, but it will be somewhere between 5 and 20 minutes.

Delays are common in radiotherapy departments. Radiotherapy machines are designed so that they don't work if anything is even slightly wrong. The good news is that this helps to make your treatment very accurate and as safe as possible. The bad news is that it can take extra time, so bring along a book or some music to listen to just in case. This kind of radiotherapy does not make you radioactive, and there will be no risk to those close to you.

The radiotherapy itself is completely painless, but it can have uncomfortable side effects.

The side effects of radiotherapy are discussed on pages 66-71



Summary

- Radiotherapy for high grade non-Hodgkin lymphoma is most often used in combination with chemotherapy.
- Radiotherapy is given Monday to Friday over a period of 4 – 6 weeks.
- The radiotherapy team will carefully make a computer plan particular to you. Your skin will be marked and these marks should remain visible until the end of your treatment.
- Radiotherapy is painless. It does not take long to have each dose of treatment, but delays are common in radiotherapy departments.

About Stem Cell Transplants

This section will discuss

what stem cell transplants are

how stem cell transplants are given

Some people with high grade non-Hodgkin lymphoma need high doses of treatment to treat their disease. These people might include:

- people with relapsed disease, meaning disease that comes back after their first treatment
- people who are considered to be at high risk of relapse
- people whose disease does not respond to regular treatment
- people involved in a particular clinical trial.

Treatment for lymphoma causes damage to the cells of your bone marrow. Your bone marrow makes the cells of the blood, so it is a vital part of our body. The large doses of chemotherapy or radiotherapy kill all the cells of your bone marrow, so your bone marrow needs help to recover.

Your bone marrow recovers with a transfusion, or a 'transplant', of cells. These cells are called stem cells. They are the primitive cells that have the potential to grow into all the different T-cells of your body. Following the transplant, they find their way back to your bone marrow, and replace the damaged cells.

A transplant can involve using your own stem cells – an autologous transplant – or someone else's stem cells – an allogeneic transplant. In most cases, stem cell transplants for

high grade non-Hodgkin lymphoma use a person's own stem cells.

Most people have to stay in hospital for a stem cell transplant. This takes around 4-6 weeks. Some hospitals offer stem cell transplants as an outpatient, meaning that people go home between the different stages. This is not widely available in the UK at present.

Collection of stem cells

Stem cells are collected from your blood or from your bone marrow. This is also called stem cell 'harvesting'.

Before harvesting begins, you will be given injections of drugs called growth factors to boost the numbers of stem cells in your blood.

If the cells are to be collected from your blood, you do not usually need to stay in hospital overnight. The cells are harvested using a machine connected to your central line, or to a tube in your arm. The machine filters out stem cells from your blood and collects them for freezing in little bags. This process takes 2 – 3 hours at a time. It may need to be repeated 2 or 3 times. On rare occasions, it may not be possible to harvest sufficient cells.

If your stem cells are to be collected from your bone marrow, you will have to stay in hospital. You will be given a general anaesthetic, and the cells will be taken from the marrow in the bone of your pelvis when you are unconscious. You will be able to go home soon after, but you will be sore. You will be given painkillers. You may need a blood transfusion if the procedure leaves you without enough red blood cells.

Conditioning

Conditioning is the name given to the high dose chemotherapy and / or radiotherapy that will be used to treat your lymphoma.

Chemotherapy will be given in much the same way as your previous chemotherapy, but you will need to stay in hospital. It is usually given using a central line.

If you are having radiotherapy, it will be given on 2 to 3 consecutive days.

The exact treatment you have will depend on your individual situation. Different combinations of drugs and radiotherapy are used.

You will have the same side effects as those described in the table on pages 72-77. You will be given medication to help reduce the side effects as much as possible.

The transplant

The stem cells are given back to you in the same way as a blood transfusion. They are in a small bag, which is connected to a tube and then given to you through your central line.

Most people do not have side effects from the stem cells, but you may have a reaction to the preservative used when the cells are frozen. These side effects include change in taste, flushing, and a distinctive smell on your breath.

Recovery

Following the transplant, the stem cells find their way back to your marrow. They then start to grow and replace your blood cells. This process is called engraftment.

The recovery of the cells in your blood usually occurs within two – three weeks of the infusion of stem cells. It may happen sooner.

During this time you will be more at risk of infection. The hospital will have rules about visitors and what visitors are allowed to bring in. For example, there will be some foods that will put you at risk of infection. The hospital will advise you about this.

You will find intravenous chemotherapy discussed on pages 54-55



Cancerbackup produces a booklet about stem cell and bone marrow transplants. You can contact them on 0808 800 1234

The most important cells to engraft are the neutrophils, which fight infection. A growth factor (GCSF) may be given to make this happen sooner. It is relatively common for people to have transfusions of red blood cells and platelets during this time.

You will be allowed to go home once your blood cells have recovered to a safe level. Most people stay in hospital for 4 – 6 weeks on average.



The Lymphoma Association produces more information on stem cell and bone marrow transplants. Please telephone the helpline

Summary

- Stem cell transplants are used in some cases of high grade non-Hodgkin lymphoma.
- Stem cell transplant for high grade lymphoma usually uses a person's own cells.
- Stem cell transplant allows for treatment with high dose chemotherapy. Infusions of stem cells allow recovery of bone marrow function.
- Following stem cell infusion there is a period of neutropaenia when there is a high risk of infection.
- Most people stay in hospital for an average of 4 – 6 weeks.

About monoclonal antibody therapy

Monoclonal antibody therapies are often used in the treatment of high grade non-Hodgkin lymphoma. They are usually used in combination with chemotherapy.

This section will discuss:

What monoclonal antibody therapy is

How monoclonal antibody therapy is given

The side effects of monoclonal antibody therapy

What is antibody therapy?

All cells have substances on their surface, called antigens. A monoclonal antibody is a protein made to recognise a specific antigen that is more common on the surface of lymphoma cells than normal cells. When the antibody recognises the antigen on the lymphoma cell it attaches itself to the antigen. This helps the cell to die, and helps your immune system to attack it.

Monoclonal antibody therapy is different from chemotherapy and radiotherapy. It is different because it targets the lymphoma cell more specifically.

Monoclonal antibody therapy takes longer to work than chemotherapy and keeps working in your body for longer.

There are now many antibodies in use for different kinds of cancer. The monoclonal antibody most often used for lymphoma is called rituximab or Mabthera®. It is usually given in combination with chemotherapy. Rituximab is only used for B-cell lymphomas.

How is antibody therapy given?

Rituximab for high grade non-Hodgkin lymphoma is given in combination with chemotherapy. It is given with each cycle of treatment.

Rituximab is given as a drip in the same way as other intravenous drugs. The first infusion is given quite slowly to help prevent side effects. This usually takes around 4 – 6 hours. Subsequent infusions may be given over a shorter period of time if you do not have significant side effects.

Rituximab is usually given as an outpatient, so you don't have to stay in hospital. Sometimes people are asked to stay in hospital following the first infusion of rituximab.

Side effects of monoclonal antibody therapy

The most common side effects of antibody therapy are shivers, fevers, and flu-like symptoms. These are more common with the first infusion, which is why the first one takes longer.

Side effects are usually easy to treat. You will be given drugs to prevent side effects. Occasionally people have more serious side effects and your doctor may decide to discontinue antibody therapy.

Summary

- Monoclonal antibody therapies are given in conjunction with chemotherapy for some high grade non-Hodgkin lymphomas.
- They work by attaching to the lymphoma cell and helping it to die.
- They are given through a drip.
- You may have to stay in hospital after the first dose. Otherwise, it is given as an outpatient.
- You may experience flu-like symptoms as a side effect. You will be given drugs to prevent this.

Side effects of treatment

This part of the booklet discusses:

common side effects of treatment for high grade non-Hodgkin lymphoma.

tips for coping with side effects.

The text written in italics refers to side effects of radiotherapy

Common side effects

It is not possible to say what side effects you will have from your treatment. Everyone will be slightly different.

The side effects of chemotherapy will depend on what drugs you are having. You will be given information about what to expect.

The side effects of radiotherapy will depend on what part of your body is being treated. You will be given information about what to expect and how to take care of yourself. You may find that you have no side effects to start with but that they become more obvious towards the end of your course of treatment.

Most treatment side effects are short term. Some may be long term or permanent. Your doctors should discuss this with you before treatment starts.

It is important to let your medical team know about your side effects. Tell them if any of the side effects change during your treatment. Your doctors and nurses won't always ask how you are feeling, and they might assume you are OK if you don't say anything. There are usually things that can be done to help with side effects.



For information about the long term side effects of treatment please telephone our helpline

Risk of infections and the blood count

The most important side effect of chemotherapy is damage to the bone marrow. The bone marrow is responsible for producing the body's blood cells. These include white blood cells that help us to fight infection.

A low white cell count means you will be more at risk of infection during your treatment. You will be most at risk from about 7 - 10 days after each dose. A low white cell count can last for some time.

You should contact your hospital if you develop signs of an infection. You will find these described in the table on page 72.



If your white cell count is too low, it may be necessary to delay treatment for a short period to give your blood count a chance to recover.

Sometimes other blood cells can be affected by chemotherapy, such as red blood cells that carry oxygen, and platelets that help to stop bleeding. For this reason, you will have regular blood counts taken during your treatment.

Your white cell count can be affected by radiotherapy too, and you will be more at risk of infection during treatment.

Change in taste and other dietary problems

Most people find that they have some problems with eating and diet. For example, food may start to taste different. You may lose your appetite. You may find that nausea or a sore mouth makes it difficult to eat. You may experience loss of weight.

If you are having radiotherapy to the chest or neck, you may also find that swallowing becomes difficult.

Feeling sick

Some chemotherapy drugs may make you feel sick – or nauseous – after treatment. You might vomit too. You will be given anti-sickness drugs to help. These are called 'anti-emetics'.

Tell your specialist or nurse how you are feeling. If the drugs don't work, tell someone. Sometimes a change in the anti-sickness drug is needed if the first drug doesn't work.

Sometimes radiotherapy can make you feel sick, in particular if your abdominal area is being treated. It may help to have anti-sickness medications before each treatment starts.

Fatigue

Fatigue is one of the most common experiences for people with lymphoma.

Cancer related fatigue is quite different from normal tiredness. It can mean that you find it difficult to concentrate or make decisions. You might be short tempered. You might sometimes feel too tired to do even simple things, like watching television. Fatigue can be difficult to describe, and you may find that other people – even your doctors – don't really understand it.

Fatigue is thought to be the result of a combination of factors, including your treatment, the impact of your illness on your body, a low red cell count ('anaemia') and anxiety.

It may take some months following treatment before your fatigue goes away.

Fatigue is associated with both chemotherapy and radiotherapy.

Hair loss

Chemotherapy drugs commonly cause hair loss. This means that you may lose some or all of your hair. Hair loss will start within a couple of weeks of starting treatment. It can come out in large quantities, and this can be very distressing.

Hair loss will only be short term, and your hair will grow back after treatment has finished. It usually starts to grow back within a month or two of treatment finishing. It might take 6 – 12 months for it to return to normal.

If you are having radiotherapy, hair loss should only occur in the area to be treated. This hair loss will be temporary, and hair will start to grow back a few months after treatment.

Sore mouth

Chemotherapy drugs may give you a sore mouth. This is because the chemotherapy damages the cells of the lining of your mouth. You will be more at risk of mouth ulcers and infections. This is called mucositis. It can be very uncomfortable.

If you are having radiotherapy to the head, neck or upper chest you may find that your mouth or throat becomes sore.

Sore skin

The skin in the radiotherapy treatment area can become pink, dry and itchy. If you have dark skin it might become darker. Sometimes it becomes blistered, a bit like sunburn. This is particularly likely to occur in folds of skin such as under the breast or in the groin. Skin reactions usually peak a few days after the end of treatment and then start to heal. You will be given instructions about caring for your skin. You may be asked to avoid bathing the area.

Peripheral neuropathy

Some chemotherapy drugs cause damage to the nerves that carry information about touch, temperature, pain and sensation. The drugs can also damage the nerves involved in muscle movement. This is called peripheral neuropathy. Peripheral neuropathy is usually related to a particular group of drugs, which includes Vincristine and Vinblastine.

Peripheral neuropathy commonly affects the nerves in your hands and feet, but you might feel it in other places too. It can cause pins and needles, pain and numbness. It sometimes causes clumsiness and problems with balance. Sometimes it produces increased sensitivity to heat.

Symptoms of peripheral neuropathy usually develop soon after you start treatment. For most people these will be temporary. Some people will experience long term or permanent damage.

Not everyone will get peripheral neuropathy. If you do experience symptoms, tell your doctor. Your doctors might make a change to your treatment to prevent it getting worse.

Reduced fertility

Many people become parents after treatment without any problem. But some treatments for lymphoma may reduce your fertility. This is particularly the case with certain chemotherapy drugs, with radiotherapy to the groin, and with high dose chemotherapy used in bone marrow and stem cell transplant.

Your consultant should discuss this with you before treatment starts, but it will not be possible to say for certain how your fertility might be affected.

Men may wish to consider storing sperm. It may be difficult for you to produce samples with lots of healthy sperm. This is because serious illness can reduce your sperm count. But developments in fertility treatment mean that fertilisation may still be possible, even with very few sperm in the sample.

The options for women are more limited. Storage of embryos takes some time, and will mean a potentially risky delay in starting your lymphoma treatment. Egg storage technology is still in its early stages, and is not in wide use at present. Talk about these things with your consultant.

Reduced fertility in women is related to age. Women closer to the age of normal menopause are more likely to experience reduced fertility, and may experience early menopause. You may find that your periods become irregular, or stop altogether during treatment. Following treatment they may return to normal, but some women will find that the irregularity continues when treatment has finished.

Sex during treatment

There is no reason why you should not have sex during treatment if you feel like it.

You may find sex more uncomfortable if you have low platelets because you are more at risk of bruising. Women may experience vaginal dryness. Using a water based lubricant can help. Traces of chemotherapy usually remain in the body for up to 3 days following treatment. Condoms should be used during this time as body fluids may contain traces of chemotherapy.

Doctors will advise that women with lymphoma do not become pregnant during the time of their treatment. This can make it more difficult to treat the disease, and treatments may be harmful to the developing baby. You should continue to use contraceptives during treatment. Oral contraceptive tablets may be made less effective by your treatment, so this should be discussed with your doctor or nurse.

Tips for coping with side effects

The table on the following pages suggests ways of dealing with side effects.

Side effect	What to do
Low white cell count 'neutropaenia'	<p>Contact the hospital if you develop signs of infection such as: fever, temperature above 38°C, chills and sweating, mouth sores and ulcers, cough or sore throat, redness or swelling around sores on the skin, diarrhoea, burning sensation when passing urine, unusual vaginal discharge or itching.</p> <p>Wash well and regularly. Wash hands before meals, after using the toilet, after using public facilities. Avoid places where infection risk is increased, such as swimming pools.</p> <p>Avoid foods that contain lots of live bacteria. These include: runny cheeses, take away food, raw or undercooked eggs, peppercorns, undercooked meats and fish, and paté. Ask your nurse for information on 'clean diets'.</p> <p>Don't keep food for longer than 24 hours in the fridge.</p> <p>Take care when handling pets – avoid bites or scratches and wash your hands afterwards.</p> <p>Wear gloves for gardening.</p>
Low red cell count 'anaemia'	<p>Tell your doctor if you feel short of breath, abnormally tired or have abnormal aches and pains.</p> <p>Ask about what treatment you might have for anaemia.</p>



For more information about dealing with side effects please telephone our helpline

<p>Low platelet count 'thrombocytopenia'</p>	<p>Report bruising or bleeding. Contact the hospital immediately if you feel very unwell, faint or clammy.</p> <p>Avoid contact sports or very vigorous exercise. Take care to avoid injury when doing day to day things like cooking and gardening.</p>
<p>Change in taste and loss of appetite</p>	<p>Try to eat little and often and avoid big meals. Eat whenever you are hungry whether or not this is your usual mealtime.</p> <p>Avoid things you don't like. Try foods that taste stronger – marinated foods, savoury rather than sweet. Eat food warm rather than hot.</p> <p>Have a ready supply of things that are quick and easy to prepare.</p> <p>Try to supplement your diet with nutritious drinks, but not at mealtimes. Take drinks through a straw.</p> <p>Eat with others in a pleasant environment.</p> <p>Take exercise where possible.</p> <p>Rinse mouth before meals and practice good mouth hygiene.</p>
<p>Constipation</p>	<p>Ask your doctor if your treatment might cause constipation, and ask for advice about using laxatives to prevent it.</p> <p>Make sure you drink plenty.</p> <p>Try a hot drink in the mornings.</p> <p>Eat a high fibre diet if possible.</p>

	<p>Take gentle exercise</p>
<p>Fatigue</p>	<p>Tell your doctor.</p> <p>Take regular light exercise, such as walking Take regular rests or short naps throughout the day.</p> <p>Ask your doctor if you are anaemic, and whether any treatment will help your anaemia.</p> <p>Plan your activities: do a bit less of what is less important, and plan the important things for when you have more energy. Accept offers of help with day to day tasks.</p> <p>Aim for a good night's sleep on a regular basis.</p> <p>Eat well.</p> <p>Make time to see friends and take part in normal social activities.</p>
<p>Feeling Sick</p>	<p>Take anti sickness drugs.</p> <p>Tell someone if they don't work.</p> <p>Try travel sickness wrist bands from the pharmacy. These prevent nausea by using acupressure points. Try relaxation techniques.</p> <p>Avoid cooking smells and seek help with preparing meals.</p> <p>Eat smaller meals, cold or at room temperature.</p> <p>Keep surroundings as peaceful and clean as possible, and encourage fresh air.</p>

Hair Loss

Have hair cut short before treatment starts.
Discuss wigs with the hospital team, or try hats or scarves.

Avoid using heated rollers or hairdryers, avoid chemical treatments such as perms and hair dyes. Avoid things that pull at your hair such as rollers and tight elastics.

Use wide toothed combs and soft bristled hair brushes.

Protect the skin of your scalp from becoming dry. Avoid exposure to heat and cold.

Wearing a hair net or towelling turban to bed will help to collect hair lost overnight.

Use make up, jewellery and accessories to give you more confidence.

Peripheral Neuropathy

Tell your doctors if you have pins and needles or loss of feeling in fingers and toes, loss of balance, abdominal pain or constipation.

Take care to avoid injury to fingers and toes, which will be less sensitive than usual: avoid extreme temperatures, wear gloves for gardening, take care when cooking. Keep your feet and hands warm as cold can make symptoms worse.

Try gentle massage and exercise of fingers and toes by flexing and stretching for a few minutes four times a day.

Wear comfortable shoes – avoid high heels or shoes that are tight.

Inspect your feet regularly to check for damaged

	<p>skin in parts that are numb, particularly on the soles of your feet and around toenails.</p>
<p>Sore mouth, sore throat.</p>	<p>Visit your dentist before starting treatment.</p> <p>Practice good oral hygiene – the hospital may prescribe special mouthwashes for use at home. Avoid mouthwashes containing salt or alcohol.</p> <p>Use a soft bristled toothbrush.</p> <p>Avoid alcohol and tobacco.</p> <p>Rinse mouth after meals.</p> <p>Keep your lips moist with lip creams. Vaseline works well and is easy to find.</p> <p>Avoid hot, spicy foods or foods coarse in texture. Cool, easy to swallow things can help, like ice cream and yoghurt.</p> <p>Sip drinks through a straw.</p> <p>Ask for pain killers or other medication to help.</p>
<p>Sore skin</p>	<p>Ask your team for instructions about looking after your skin.</p> <p>Do not use creams unless recommended by your specialist. Avoid soaps, talcum powder and deodorants.</p> <p>Avoid rubbing the skin. If bathing, use lukewarm water and pat dry with a towel.</p> <p>Men having radiotherapy to the head or neck should use electric razors rather than wet shaving, or avoid shaving altogether.</p>

	<p>Avoid exposure to sun and wind.</p> <p>Avoid swimming pools.</p>
Reduced fertility	<p>Talk about fertility with your doctor before treatment starts.</p> <p>Discuss options for storage of tissue for use after treatment if necessary.</p> <p>Women should continue to use contraceptives during treatment.</p>

About your hospital

People with lymphoma may be treated at local hospitals or at larger hospitals with cancer centres. Sometimes people will have their treatment shared between the two.

Your GP, or the doctor who finds out that you have lymphoma, will send you to the nearest hospital with a lymphoma specialist. Don't worry if you are having treatment at a small hospital. Larger hospitals do not necessarily have better results.

A lymphoma specialist might be a haematologist (someone who specialises in diseases of blood cells) or an oncologist (someone who specialises in cancers). Lymphoma experts come from both these fields of medicine.

Your doctor will not mind if you want to ask questions about your treatment hospital. Some of the questions you might like to ask are:

- Will your doctor have links with other lymphoma specialists?
- Does the hospital have a clinical nurse specialist or other specialist cancer nurse?
- Does the hospital have a laboratory on site for fast blood test results?
- Does the hospital have close links with specialist lymphoma pathologists?
- Does the hospital participate in clinical trials?
- What other experts are there to help if you need them? For example, will you be able to see a dietician, or a counsellor if you need to?



The Lymphoma Association has a fact sheet about hospitals and seeking second opinions. Please telephone the helpline for a copy

Clinical trials

Clinical trials are scientific studies that test the success of different treatments. They are very important in improving the future treatment of people with lymphoma. You may be invited to take part in one. Not all hospitals conduct clinical trials. This may be something to discuss with your doctor when planning treatment.

The treatments involved will always be treatments that are known to work against high grade non-Hodgkin lymphoma. You are not going to be offered a treatment that no one has heard of before.

Clinical trials for high grade non-Hodgkin lymphoma usually involve comparing a standard treatment with another, newer, type of treatment. People involved are allocated to one of two groups. You will not be able to choose which of the treatments you receive. You will be put into one of the groups at random.

If you take part in a trial, you will be given information about the reasons for the trial and the drugs you will have.

Clinical trials often involve more tests and scans. People involved in trials also have access to specialist research staff for information during treatment and afterwards.

There should be no pressure placed on you to take part in a trial if you do not wish to. You can always opt to have the standard treatment if you prefer.

Summary

- High grade non-Hodgkin lymphoma is treated by either a haematologist or an oncologist
- High grade non-Hodgkin lymphoma is treated at both small and large hospitals. Large hospitals do not necessarily have better results.
- You may be asked if you wish to take part in a clinical trial. Clinical trials usually compare one kind of treatment with another. You will not be able to choose which treatment you will have.
- You do not have to take part in a clinical trial if you don't want to.

After Treatment

This section will discuss:

what is meant by remission and cure

what happens when treatment has finished

what happens if the lymphoma comes back

Remission and cure

Remission means that the lymphoma has been reduced or eliminated completely.

There are different degrees of remission. A partial remission is where the disease has been significantly reduced but not removed altogether. A complete remission is where no evidence of the disease is present.

Specialists treating high grade non-Hodgkin lymphoma will aim to cure it. They will aim for a long-term complete remission.

You may find that your specialist prefers to say 'you are in remission' rather than 'you are cured'. This is because they cannot say for certain whether or not your disease will come back. But the longer you have been in remission, the less likely it is that your disease will come back.

Follow up appointments

You will see your specialist on a regular basis when you are in remission.

You will have regular appointments to start with. This might be once a month. If you stay well, the appointments will be reduced to every 6 months and eventually to only once a year.

People who have had high grade lymphoma will usually see their specialists for several years after the end of their treatment.

The follow up appointments are to check that you are still in remission. Your specialist will also want to see if you have recovered from your treatment. He or she will ask how you have been feeling, and you will have a brief physical examination. You may have more blood tests.

If you are worried about your health at any time, you don't have to wait for your next appointment. Contact your GP or specialist.

Most people become very worried about their follow up appointments, and you might not want to go back to see your specialist. But these appointments are an important part of your care. They give you a chance to talk about anything that might be on your mind. It can help to write these things down when you think of them, and take a list of questions with you.

What happens if the lymphoma comes back

In some cases, lymphoma can come back following the initial course of treatment. This is called a relapse.

If you do experience a relapse, your specialist will want to repeat some of the tests you had to start with. Further treatment will be planned on the basis of your individual situation.

Relapse of high grade non-Hodgkin lymphoma is more likely to happen within the first two years of remission.

It may be possible for you to have further treatment for relapsed high grade non-Hodgkin lymphoma. The treatment will depend on your overall health and what treatment you had before. People in this situation may be offered treatment with chemotherapy or with a bone marrow or stem cell transplant. Antibody therapies may also be used.

Summary

- Complete remission means that there are no signs of your lymphoma left.
- You will have check ups for some years after your treatment has finished. These will be regular to start with, and gradually reduce to once every 6 months – 1 year.
- You don't have to wait until your next appointment if you are worried about anything. Contact the clinic or your GP to talk about it.
- Sometimes, lymphoma can come back after initial treatment. This is called 'relapse'. Treatment for relapsed lymphoma depends on the individual situation.

Whatever your situation, we hope that this booklet has helped you to understand more about high grade non-Hodgkin lymphomas, and what you might expect of your experience.

Please do not hesitate to get in touch with the Lymphoma Association Helpline if you require further information about lymphomas and treatment or if you would like information about living with lymphoma.

Glossary

AIDS	Acquired Immune Deficiency Syndrome. A situation in which a person's immune system is no longer able to fight off or prevent infection as a result of infection with HIV.
Allogeneic	the use of someone else's tissue (eg bone marrow)
Anaemia	shortage of red blood cells in the blood
Anaesthetic	drugs given to make a part of the body numb (a local anaesthetic) or the whole body numb (a general anaesthetic)
Antibody	A protein that kills off disease causing cells or organisms such as bacteria
Autologous	the use of a person's own tissue (eg bone marrow)
Alopecia	loss of hair
Bacteria	small organisms, some of which can cause disease
Biopsy	a test that takes some cells to be looked at under a microscope
Blood count	A blood test that counts the different types of cells in your blood. This includes the red blood cells, the different types of white blood cells, and platelets.
Bone marrow	spongy material at the centre of long bones that produces the body's blood cells
Chronic	Something that is long term and doesn't go away completely.
CT / CAT scan	stands for "computerised tomography" or "computerised axial tomography". A test that gives a layered picture of the inside of the body.

Diagnosis	Naming a condition or disease
Diaphragm	the layer of muscle that lies below the lungs. It divides the body between chest and abdomen
Fine needle aspiration	a test that takes some cells from a lump using a needle and syringe
Fungus	a type of organism that can cause disease
Haematologist	a doctor specialising in diseases of the blood and blood cells
Histology	the study and description of diseased cells
HIV	Human Immunodeficiency Virus. A virus that leads to a deficiency in part of the immune system
Immune system	the parts of the body that fight off and prevent infection
Intravenous	into a vein
Lymph	the straw-coloured fluid that carries material through the lymphatic system
Lymphatic vessels	the tubes that carry lymph and connect with the lymph nodes
Lymph node	gland that forms a sieve in the lymphatic system. Involved in fighting infection
Lymphoedema	swelling caused by a blockage to the lymphatic system
Malignant	cancerous; a tumour that can spread to other parts of the body
Monoclonal Antibody therapy	treatment that uses a manufactured antibody to target and kill malignant T-cells
MRI	a test using magnetic rays to give a picture of the body. Stands for Magnetic Resonance Imaging
Neutropenia	shortage of neutrophils in the blood. Neutrophils are a type of white blood cell
Oncologist	a doctor specialising in the treatment of cancer

Pathologist	a person who examines diseased tissues
Platelets	The cells of your blood that help it to clot and stop bleeding.
Prognosis	an estimate of the future course of a person's illness
Radiographer	a person who takes x-rays or gives radiotherapy
Radiologist	a doctor who can interpret x-rays and scans
Radiotherapist	a doctor who specialises in radiotherapy (sometimes called a clinical oncologist)
Spleen	a large organ that sits behind the stomach. Involved in the immune system, also removes worn out red blood cells
Subcutaneous	underneath the skin
Symptom	a change in the body or its functions that tells you something is abnormal
Thrombocytopenia	shortage of platelets in the blood. Platelets help to stop bleeding
Tumour	collection of cells to form a lump
Tumour markers	chemicals produced by tumour cells that can be found in the blood
Virus	a tiny organism that causes disease. Unlike bacteria, viruses are not made up of cells

Other useful organisations

The following are useful sources of information about disease and treatment. The Lymphoma Association has details of many organisations dealing with all aspects of life with cancer, so do get in touch for more information.

Cancerbackup

3 Bath Place, Rivington Square, London EC2A 3JR
Tel: 0808 800 1234

Website www.cancerbackup.org.uk

Infertility Network UK

Charter House, 43 St Leonards Road, Bexhill-on-Sea, East Sussex TN40 1JA

Advice line: 08701 188 088

Website: www.infertilitynetworkuk.com

Leukaemia Research Fund

43 Great Ormond Street, London WC1N 3JJ
Tel: 020 7405 0101

Website: www.lrf.org.uk

Email: info@lrf.org.uk

Funds research into the causes and treatment of leukaemia, lymphoma and related diseases. Publish booklets on a range of subjects.

Macmillan Cancer Support

89 Albert Embankment, London SE1 7UQ

Tel: 0808 808 20 20

Website: www.macmillan.org.uk

Email: cancerline@macmillan.org.uk

A national charity providing information and support for patients and carers. Macmillan fund specialist nursing and medical services for people with cancer.

Terence Higgins Trust

Branches nationwide

0845 12 21 200

Website: www.tht.org.uk

Europe's largest provider of information, support, and education about HIV and AIDS.

Selected references

This booklet has been prepared with reference to a number of Lymphoma Association publications commissioned from members of our medical advisory panel. These include:

Autologous Stem Cell Transplant (December 2004)
Cancer Related Fatigue (revised May 2005)
Causes of non-Hodgkin lymphoma (revised May 2005)
Lymphoma Classification: Why does it matter? (revised Spring 2006)
Mantle Cell Lymphoma (December 2004)
Nutrition and Lymphoma (revised June 2005)
Oral Problems Associated with Chemotherapy and Radiotherapy (September 2003)
The Central Nervous System and Lymphoma (September 2004)

Other references include:

Textbooks:

Hancock, B.W., McLennan, K., Armitage J.O., (eds.), *Malignant Lymphoma*, London: Hodder Arnold, 2000
Otto SE. *Oncology Nursing. Third edition.* St Louis: Mosby, 2000.
Provan D, Chisholm M, Duncombe A, et al., *Oxford Handbook of Clinical Haematology: Second Edition*, Oxford: Oxford University Press, 2004.

Journal articles:

Adamsen, L. et al, 'The effect of a multidimensional exercise intervention on physical capacity, well being and quality of life in cancer patients undergoing chemotherapy', in *Supportive Care in Cancer*, 2006 Feb; 14(2): 116-27
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Evans, L.S., Hancock, B.W., 'Non-Hodgkin lymphomas' in *The Lancet*, Volume 352, July 12, 2003
Sehn L, Donaldson J, Filewich A, et al., 'Rapid infusion rituximab can be safely administered and has a positive impact on resource utilization' in *Blood* 2004; 104: 394a
Weiss R., et al, 'Acquired immunodeficiency syndrome-related lymphoma: simultaneous treatment with combined cyclophosphamide, doxorubicin, vincristine, and prednisone chemotherapy and highly active antiretroviral therapy is safe and improves survival-Results of the German Multicenter Trial' in *Cancer* 2006 Apr 1; 106(7):1560-8
Incidence of non-Hodgkin lymphoma, UK, 2002,
<http://info.cancerresearchuk.org/cancerstats/types/nhl/>
accessed March 2006



The Lymphoma Association provides:

- freephone helpline 9am-6pm Monday - Thursday, 9am-5pm Friday
- emotional support for those affected by lymphomas
- information about lymphomas and their treatments
- audio and video library
- telephone links to others with similar experience of lymphoma
- quarterly newsletter
- network of support groups
- national and regional patient conferences
- websites
- Lymphoma Nurse Specialist pilot programme

Publisher: Lymphoma Association

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