

# Non-Hodgkin lymphoma

**J A S C A P**

**JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, MUMBAI,  
INDIA**

## **JASCAP**

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS  
c/o. Abhay Bhagat & Co., Office No.4, "Shilpa", 7<sup>th</sup>.Road, Prabhat Colony,  
Santacruz (East), Mumbai – 400 055  
Tel.: 2617 7543, 2616 0007. Fax: 91-22-2618 6162  
E-mail :pkrjascap@gmail.com & abhay@abhaybhagat.com

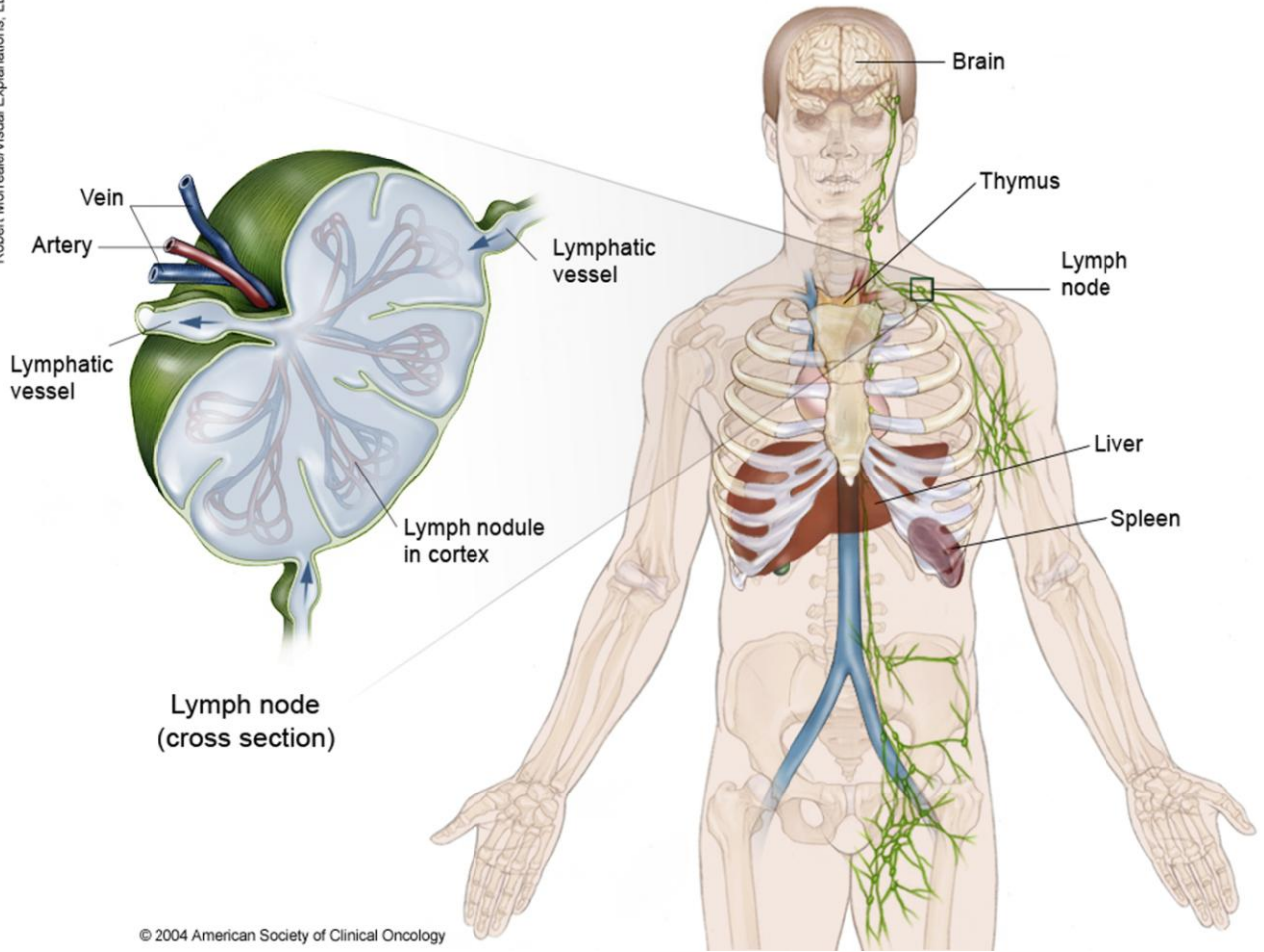
JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

Registered under the Societies Registration Act, 1860 No.1359 / 1996 G.B.B.S.D., Mumbai and under the Bombay Public Trusts Act, 1950 No. 18751 (Mumbai). Donations to JASCAP qualify for deduction u/s 80G (1) of the Income Tax Act, 1961 vide Certificate No. DIT (E) / BC / 80G / 1383 / 96-97 dated 28.02.97 subsequently renewed.

**Contact: Mr. Prabhakar K. Rao or Mrs. Neera P. Rao**

**Donation suggested Rs.25.00**

- o © Cancerbackup January 2009
- o This booklet is an adaptation of "understanding non-Hodgkin lymphoma" produced by Cancerbackup and is reproduced with their kind permission.
- o JASCAP gratefully acknowledges Cancerbackup's permission to reproduce this booklet.



## Contents

### General

- What is lymphoma?
- The lymphatic system
- What is NHL?
- Types of NHL

### Causes & diagnosis

- Causes
- Symptoms
- Diagnosis
- Further tests
- Grading & staging

### Treatment

- Treatment overview
- Chemotherapy
- Steroid therapy
- Monoclonal antibodies
- Radiotherapy

### After treatment

- Follow up
- If NHL comes back
- Fertility

### Clinical trials

- Research - clinical trials

### Types of NHL

- Anaplastic large cell \*\*
- Burkitt \*\*
- Cutaneous T-cell \*\*
- Diffuse large B-cell \*\*
- Follicular \*\*
- Lymphoblastic \*\*
- MALT \*\*
- Mantle cell \*\*
- Mediastinal large B-cell \*\*
- Nodal marginal zone B-cell \*\*
- Peripheral T-cell \*\*
- Small lymphocytic \*\*
- Thyroid \*\*
- Waldenstrom macroglobulinaemia \*\*

### Resources & support

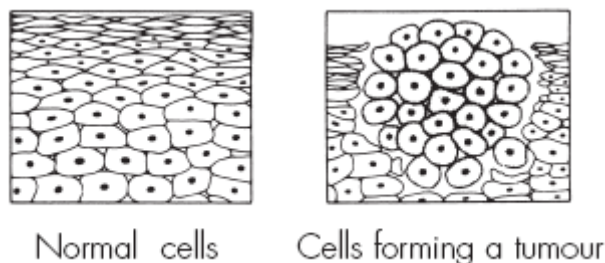
- JASCAP resources

**\*\* JASCAP has factsheets on each of these sub-types of NHL.**

## What is lymphoma?

Lymphoma, like other cancers, is a disease of the body's cells. Cells in different parts of the body work in different ways, but they all repair and reproduce themselves in the same way.

Normally, cells divide in an orderly and controlled manner. However, if for some reason the process gets out of control the cells carry on dividing. There may be too many immature white blood cells in the blood or bone marrow, which may cause a lump or tumour to develop in one or more groups of lymph nodes.



Lymphoma cells generally start to grow in lymph nodes, which are part of the lymphatic system.

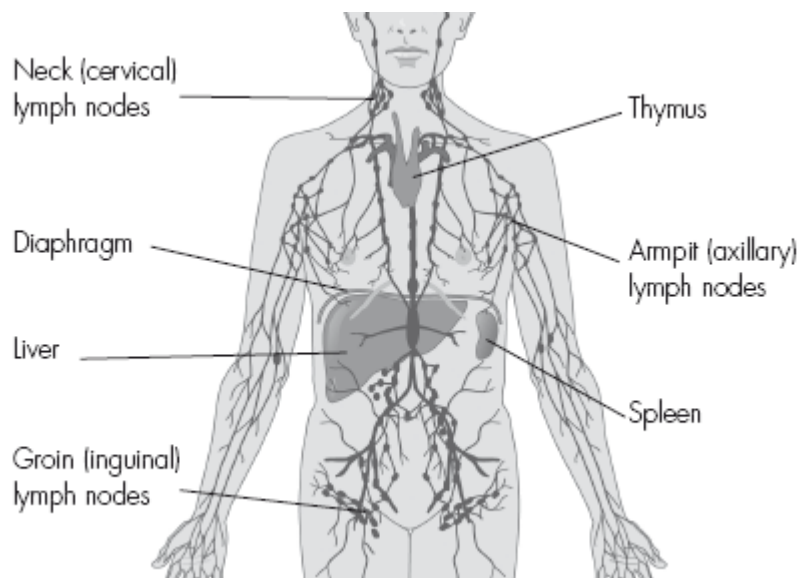
Usually non-Hodgkin lymphoma (NHL) affects groups of lymph nodes in one area of the body. However, the lymphoma cells can sometimes spread through the lymphatic system to lymph nodes in other parts of the body. They can also go into the bloodstream, which may carry them to other organs. When the cells reach a new area they may go on dividing and form a new tumour.

There are lymph nodes and lymph vessels throughout the body, so NHL can occur in any part of the body. The most common place is in the lymph nodes in the neck. The next most common places are the lymph glands under the arms (axilla), in the chest, or in the groin or abdomen. It can also occur in organs. In some people NHL can affect the liver, lungs or bone.

Most lymphomas are lymphomas of the B-cells; however there are also some which are lymphomas of the T-cells. These occur more commonly in teenagers and young adults.

## The lymphatic system

The lymphatic system is one of the body's natural defences against infection. It is a complex system made up of lymphatic organs, such as bone marrow, tonsils, the spleen, and lymph nodes (also called lymph glands). They are connected by a network of tiny lymphatic vessels. Lymph nodes are mainly found in the neck, armpit and groin. The number of nodes varies from one part of the body to another. In some parts there are very few. However, under your arm there may be between 20 and 50 nodes (see the diagram below).



The lymphatic system

A milky-looking fluid called lymph circulates through the lymphatic vessels. Lymph contains lymphocytes, which are white blood cells. Lymphocytes are an essential part of the body's defence against infection and disease. For example, if you have a sore throat, you may notice that the lymph nodes in your neck get bigger. This is a sign that your body is fighting the infection.

There are two main types of lymphocyte: **B-cells** and **T-cells**. All lymphocytes develop in the bone marrow from immature cells called stem cells. Lymphocytes then mature in different parts of the body. Lymphocytes which mature in the thymus gland (behind the breast bone) are called T-cells. Other lymphocytes mature in the bone marrow or lymphatic organs and are called B-cells.

## What is non-Hodgkin lymphoma?

Non-Hodgkin lymphoma, also known as NHL, is a type of cancer of the lymphatic system. There are two main types of lymphoma. One is called Hodgkin lymphoma, which used to be called Hodgkin's disease. The other is non-Hodgkin lymphoma.

About four in five (80%) of all lymphomas diagnosed are non-Hodgkin lymphoma. Over 9700 people in the UK are diagnosed with non-Hodgkin lymphoma each year.

### *The difference between NHL and Hodgkin lymphoma*

It is only possible to tell the difference between Hodgkin and non-Hodgkin lymphomas, when the cells are looked at under the microscope. Often the cells need to be stained to show their structure in detail. Usually the cells will be tested for the presence of particular proteins – this is known as **immunohistochemistry**.

Another test, called **molecular analysis**, looks at specific gene changes in the cells. This also helps reveal the type of lymphoma.

In most cases of Hodgkin lymphoma, a particular cell known as the **Reed-Sternberg cell** is found in the biopsies. This cell is not usually found in other lymphomas, so they are called non-Hodgkin lymphoma. This may not seem a very big difference, but it is important because the treatments for Hodgkin and non-Hodgkin lymphomas are very different.

There are many different types of NHL, some of which are more common than others.

## Types of non-Hodgkin lymphoma

There are different ways of dividing up, or classifying, NHL. Different lymphomas are treated in different ways so it is important that the doctors know which type it is. The cells are examined and tests done which tell the doctors what type it is. The tests include looking at the appearance of the cells under the microscope, testing for specific types of proteins in the cells, and looking at genetic changes in the cells.

The most commonly used classification system groups lymphomas according to the cell type. There are over 20 different types of non-Hodgkin lymphoma.

### ***B-cell lymphomas***

B-cell lymphomas are more common than T-cell lymphomas. The most common types of B-cell lymphomas are:

- diffuse large B-cell lymphoma
- follicular lymphoma.

Other types which are less common include:

- extranodal marginal zone B-cell – MALT
- mantle cell
- burkitt lymphoma
- mediastinal large B-cell lymphoma
- nodal marginal zone B-cell lymphoma
- small lymphocytic lymphoma
- lymphoplasmacytic lymphoma (also called Waldenstrom's macroglobulinaemia).

### ***T-cell lymphomas***

T-cell lymphomas are much less common. Again there are a number of different types. These include:

- peripheral T cell lymphoma
- skin (cutaneous) lymphomas – including Mycosis fungoides and Sézary syndrome
- anaplastic large cell
- lymphoblastic lymphoma (mainly T-cell but can be B-cell).

For other rare types of lymphoma, contact our cancer information service where we can give you more information about your illness and its treatment.

## Causes of non-Hodgkin lymphoma

The cause of most non-Hodgkin lymphomas is unknown. However, lymphomas are more likely to develop in people who have taken drugs to prevent rejection of an organ transplant or who have lowered immunity, for example due to HIV or Aids. Despite the increased risk, NHL is still uncommon in people with these conditions.

Non-Hodgkin lymphoma is also slightly more common in people who have been treated for cancer before. Some chemotherapy drugs and radiotherapy treatments can increase a person's risk of developing NHL many years later. The risk is very small, however, compared to the benefit of having the treatment in the first place.

Certain viruses, such as the Epstein-Barr virus, which causes glandular fever, or the human T-cell lymphoma virus 1 (HTLV1) can contribute to the development of lymphomas. However, like other cancers, lymphomas themselves are not infectious and cannot be passed on to other people.

One type of lymphoma, which usually affects the stomach – MALT lymphoma – is known to be caused by a type of bacterial infection known as helicobacter pylori.

People who have coeliac disease (an allergy to gluten which can cause inflammation of the small bowel) have a slightly increased risk of developing B-cell NHL or a rare type of T-cell lymphoma called enteropathy type T-cell lymphoma (ETTL).

## Symptoms of non-Hodgkin lymphoma

Often, the first sign of a non-Hodgkin lymphoma is a painless swelling of a lymph node in the neck, armpit or groin.

Other symptoms may include any of the following:

- night sweats or unexplained high temperatures (fever)
- loss of appetite, unexplained weight loss and excessive tiredness
- persistent itching of the skin all over the body
- children may develop a cough or breathlessness; they may also complain of abdominal pain or you may notice a lump in your child's abdomen.

If you have any of the above symptoms you should have them checked by your doctor. However, they are common to many conditions other than non-Hodgkin lymphoma and most people with these symptoms will not have a lymphoma.

Lymphomas that start in another part of the body may have different symptoms. For example, if the lymphoma is in the abdomen you may have abdominal pain or indigestion.

## How NHL is diagnosed

Usually, you begin by seeing your GP (family doctor) who will examine you and arrange for you to have any tests or x-rays that may be needed. Your GP will need to refer you to hospital for these tests and for specialist advice and treatment.

At the hospital, the doctor will take your full medical history before doing a physical examination. You may be asked to have blood tests and a chest x-ray to check your general health.

A definite diagnosis is made by removing an enlarged lymph node, or part of it, and examining the cells under a microscope. This is known as a **biopsy**. It may be done under local anaesthetic and sedation, or a general anaesthetic. Biopsies may also be taken from other body tissues.

## Further tests for non-Hodgkin lymphoma

If the biopsy shows that lymphoma cells are present, your doctor will want you to have some further tests to find out the exact stage of the lymphoma. Staging is a way of describing the extent and spread of the lymphoma in your body. It is very important because the type of treatment you have depends on the stage of the disease.

The tests that may be done to find the stage of your lymphoma may include any of the following:

- Blood tests
- Chest x-ray
- CT scan
- MRI scan
- Bone marrow sample



Lumbar puncture  
PET scan  
Waiting for the results

### **Blood tests**

Samples of your blood will be taken regularly throughout your treatment to check your general health, the levels of red cells, white cells and platelets in your blood, and how well your liver and kidneys are working.

### **Chest x-ray**

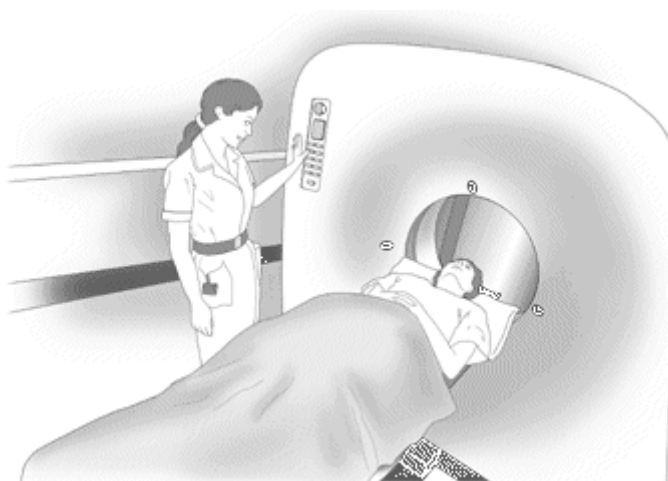
This is taken to check for any sign that the lymphoma has spread to the lymph nodes in the chest or to the lungs.

### **CT scan**

A CT (computerised tomography) scan takes a series of x-rays which build up a three-dimensional picture of the inside of the body. The scan is painless but takes from 10 to 30 minutes. CT scans use a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye which allows particular areas to be seen more clearly. For a few minutes this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it is important to let your doctor know beforehand.

You will probably be able to go home as soon as the scan is over.



Having a CT scan

### **MRI scan**

An MRI (magnetic resonance imaging) scan is similar to a CT scan, but uses magnetic fields instead of x-rays to build up a series of cross-sectional pictures of the body.

During the test you will be asked to lie very still on a couch inside a metal cylinder that is open at both ends. The whole test may take up to an hour and is painless – although the machine is very noisy. You will be given earplugs or headphones to wear.

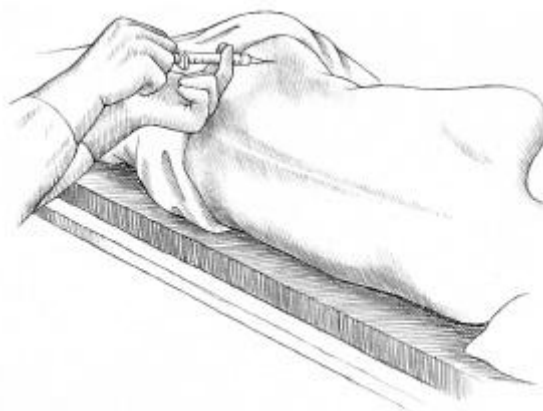
The cylinder is a very powerful magnet, so before going into the room you should remove all metal belongings. You should also tell your doctor if you have ever worked with metal or in the metal industry or if you have any metal inside your body (for example, a cardiac monitor, pacemaker, surgical clips, or bone pins). You may not be able to have an MRI because of the magnetic fields.

Some people are given an injection of dye into a vein in the arm, but this usually does not cause any discomfort. Some people feel claustrophobic inside the cylinder, but you may be able to take someone with you into the room to keep you company. It may also help to mention to the staff beforehand if you do not like enclosed spaces. They can then offer extra support during your test.

### ***Bone marrow sample***

A small sample of bone marrow is usually taken from the back of your hipbone (pelvis). The sample is looked at under a microscope to see if it contains any lymphoma cells.

The bone marrow sample is taken under a local anaesthetic. You will be given a small injection to numb the area and the doctor will gently pass a needle through the skin into the bone. The doctor will draw a small sample of liquid marrow into a syringe to be looked at later under the microscope (bone marrow aspirate). The doctor will then take a small core of marrow from the bone (a trephine biopsy).



A bone marrow sample being taken

The test can be done on the ward or in the outpatients department. The whole procedure takes about 15–20 minutes. It may be uncomfortable as the marrow is drawn into the syringe but this should only last for a few seconds. You may be offered a short-acting sedative to reduce any pain or discomfort during the test.

You may feel bruised after the test and have an ache for a few days. This can be eased with mild painkillers.

### ***Lumbar puncture***

This test is done on the ward or in the outpatient's department. First, you will be given an injection of local anaesthetic. A thin needle is then put through the skin of your back into the fluid around your spine and a sample of spinal fluid will be taken. This will be examined in the laboratory to see

if it contains any lymphoma cells. You will be asked to stay lying flat for at least an hour after the test, to reduce the chance of getting a headache.

Most people have no problems with this test, although when the needle is put in it can sometimes cause a tingling down the back of your legs. This is harmless, but can be worrying if you are not expecting it. Some people get a headache for a few days afterwards and may need to take painkillers.

### ***PET scan***

PET (positron emission tomography) scans are a new type of scan so you may have to travel to a specialist centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case. PET scans can be used to find whether a lymphoma has spread, or to examine any lumps that remain after treatment to see whether they are scar tissue or whether cancer cells are still present.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and they show up on the scan.

### ***Waiting for the results***

It will probably take several days for the results of your tests to be ready and a follow-up appointment will be arranged for you to discuss them. Obviously this waiting period may be an anxious time for you and it may help you to talk things over with a close friend, relative or a support organisation. You can ask your doctor when your results will be available, so that you know how long you will have to wait.

## **Grading and staging of NHL**

Grading refers to how quickly the lymphoma may grow and develop. Staging is a term which describes where it is in the body, how many lymph glands are affected and whether it has spread to other lymph glands or other organs.

Grading  
Staging

### ***Grading***

Most non-Hodgkin lymphomas fall into one of two main categories:

**Low-grade (or indolent)** These grow very slowly and may need little or no treatment for months or possibly years. When they do need treatment they are likely to shrink down, or even disappear completely. Some types of low-grade NHL can be cured with treatment, but others are likely to come back again at some time in the future. Follicular lymphoma is an example of a low-grade NHL.

**High-grade (or aggressive)** These types grow more quickly. They usually cause symptoms and will need immediate treatment. However, they are more likely to be completely cured than low-grade lymphomas. The usual treatment is chemotherapy. Diffuse large B-cell, and Burkitt lymphoma are types of high-grade lymphoma.

## Staging

A commonly used staging system is described below:

**Stage 1** One group of lymph nodes is affected.

**Stage 2** Two or more groups of nodes are affected, but the lymphoma is only on one side of the diaphragm. The diaphragm is the sheet of muscle under the lungs that helps us to breathe. The part of the body above the diaphragm is the upper half, and below the diaphragm is the lower half of the body.

**Stage 3** The lymphoma is on both sides of the diaphragm.

**Stage 4** The lymphoma has spread beyond the lymph nodes, for example to other organs such as the bone marrow, liver or lungs.

As well as giving each stage a number, doctors also use a letter code – either A or B – to show whether or not you have specific symptoms. Your doctor will ask you whether you have lost weight or have fevers or night sweats. If you do not have any of these symptoms, your lymphoma will be classified as A. If you have these symptoms, it is B.

Occasionally, lymphomas can occur at unusual sites outside the lymph nodes, for example in the stomach. This is called extranodal lymphoma and the stage will include the letter E (for extranodal).

Once your doctor knows the type of lymphoma and the stage and grade, they can plan the most effective treatment for you.

## Treatment for non-Hodgkin lymphoma

Many people with non-Hodgkin lymphomas can either be cured or stay in remission for many years. **Complete remission** is where there is no sign of the lymphoma. **Partial remission** is where the lymphoma shrinks down so that the person is well, does not have symptoms and does not need further treatment at that time.

Your doctor will plan your treatment by taking into consideration a number of things, including the specific type of lymphoma you have, your age, your general health (including any other medical conditions), which parts of your body are affected and the number of affected lymph nodes and whether other organs are affected.

- Low-grade lymphomas
- High-grade lymphomas
- Children
- Planning your treatment
- Giving your consent
- Benefits and disadvantages of treatment
- Treatment decisions
- Second opinion

### Low-grade lymphomas

Low-grade lymphomas often grow very slowly and there may be long periods where there is very little, or no, change in the disease. For many people, regular check-ups are all that is needed and treatment may be postponed for a long time – this is known as **active surveillance** or **watchful waiting**. Usually the first treatment given is chemotherapy, often in combination with a monoclonal antibody. If you have low-grade NHL in only one group of lymph nodes, you may just be given radiotherapy to that area.

After treatment, many people with low-grade lymphoma have a time with no signs of active disease (known as remission). If the lymphoma then comes back, it can be treated again with chemotherapy (with or without a monoclonal antibody), radiotherapy or with a monoclonal antibody given on its own. Often another period of remission may follow. Low-grade NHL can often be controlled in this way for many years.

### ***High-grade lymphomas***

These are faster growing and need treatment soon after the diagnosis. Treatment is usually with a combination of chemotherapy drugs and steroids. The chemotherapy is given into a vein by drip, often in combination with a monoclonal antibody. Most chemotherapy for high-grade lymphomas is given in the outpatients department, although sometimes you may have to stay in hospital. Chemotherapy for high-grade NHL will vary depending on the type.

If there is a risk that the nervous system may be affected by the lymphoma, an anti-cancer drug may be injected into the fluid around the spinal cord – this is called intrathecal chemotherapy.

Chemotherapy can often shrink high-grade NHL very quickly. If there is a high risk of the lymphoma coming back after standard treatment, other treatments such as high-dose chemotherapy may be recommended. Sometimes radiotherapy is used after chemotherapy, especially if the lymphoma is in just one area of the body or was very large before chemotherapy was given.

### ***Children***

Children with non-Hodgkin lymphoma nearly always have high-grade tumours and the main form of treatment is with intensive chemotherapy. Radiotherapy may sometimes be needed as well.

During the initial intensive period of a child's chemotherapy, they will probably not be able to go to school. Many children worry quite a lot about missing school and getting behind with their work. It is important to reassure them that they will be able to catch up. Your doctor and the social worker at the hospital can help you to arrange a home tutor for your child during this time.

It may help to talk to your child's head teacher, to see if the school can arrange to send work home for your child. There is also a teacher attached to the hospital ward who will help with your child's education if they have to be in hospital for extended periods. The teacher will also keep in touch with your child's school.

Our children's storybook, Peppermint Ward, covers many of the issues children face when having chemotherapy. You can order a copy of this publication.

We have a booklet on children's cancers, which has detailed information about non-Hodgkin lymphoma in children and its treatment.

### ***Planning your treatment***

In most hospitals, a team of specialists will decide the treatment that is best for you. This multidisciplinary team will include:

- a haematologist (doctor who specialises in treating blood disorders)
- medical and clinical oncologists (chemotherapy and radiotherapy specialists)
- a radiologist (a doctor who helps to analyse scans and x-rays).

It will often include a number of other healthcare professionals such as a nurse specialist, a pathologist (a doctor who specialises in identifying diseases by looking at cells in the laboratory), a dietitian, a physiotherapist, an occupational therapist and a psychologist or counsellor.

Together, the doctors will be able to advise you on the best course of action and plan your treatment.

If two treatments are equally effective for your type and stage of lymphoma, your doctors may offer you a choice of treatments. Sometimes people find it very hard to make a decision. If you are asked to make a choice, make sure that you have enough information about the different treatment options, what is involved and the side effects you might get, so that you can decide what the right treatment is for you.

Remember to ask questions about any aspects that you do not understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your doctor, or specialist nurse.

### ***Giving your consent***

Before you have any treatment, your doctor will explain the aims of the treatment to you. They will usually ask you to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment. Before you are asked to sign the consent form, you should be given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other treatments that may be available
- any significant risks or side effects of the treatment.

If you don't understand what you have been told, let the staff know straight away so that they can explain again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations.

It is often a good idea to have a friend or relative with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go to your appointment. Patients can feel that hospital staff are too busy to answer questions, but it is important to know how treatment is likely to affect you. Staff should be willing to make time for your questions.

You can always ask for more time to decide about the treatment, if you feel that you can't make a decision when it is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment, but it can be helpful to let the staff know your concerns so that they can give you the best advice.

### ***Benefits and disadvantages of treatment***

Many people are concerned about the side effects that may occur with cancer treatments. Although treatments can cause side effects, these can usually be controlled with medicines. Some people ask what would happen if they did not have any treatment.

Treatment can be given for different reasons, and the potential benefits will vary for each person. Low-grade NHL is usually very sensitive to chemotherapy and radiotherapy, and treatment can

reduce the amount of lymphoma (partial remission) or get rid of it for a time (complete remission). Many people with low-grade NHL can have the illness controlled for many years and can live an almost normal life for a lot of that time. Treatment can reduce symptoms and increase life expectancy for most people.

Without treatment, high-grade NHL would usually get bigger and spread quite quickly, and most people would not live for much longer. Most of the side effects of treatment can be well controlled and the treatment is usually effective. A complete cure is possible for many people with high-grade NHL. Some people will find that their initial treatment does not work, and then another type of treatment will be used.

Sometimes, if the lymphoma has come back after initial treatment, the treatment may only be able to control it, leading to an improvement in symptoms and a better quality of life. However, for some people in this situation the treatment will have no effect upon the cancer and they will get the side effects with little benefit.

### ***Treatment decisions***

If you have been offered treatment that aims to cure your lymphoma or put it into remission, deciding whether to accept the treatment may not be difficult. However, if your lymphoma has come back and the treatment you have been offered is to control it for a period of time, it may be more difficult to decide whether to go ahead with treatment.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have further treatment. If you choose not to, you can still be given supportive (palliative) care, with medicines to control any symptoms.

### ***Second opinion***

Even though a number of cancer specialists work together as part of a team to decide on the most suitable treatment, you may want to have another medical opinion. Most doctors will be willing to refer you to another specialist for a second opinion, if you feel that it will be helpful. The second opinion can take some time to organise and may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will be helpful.

If you go for a second opinion, it may be a good idea to take a friend or relative with you, and have a list of questions ready, so that you can make sure your concerns are covered.

## **Chemotherapy for non-Hodgkin lymphoma**

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy the lymphoma cells. The drugs travel round in the blood and reach lymphoma cells wherever they are in the body.

- Low-grade lymphoma
- High-grade lymphoma
- Intrathecal chemotherapy
- Central lines
- PICC Lines
- Implantable ports
- Side effects of chemotherapy
- Permanent side effects

### ***Low-grade lymphoma***

Low-grade lymphomas are often treated with chemotherapy tablets that can be taken at home, so you can carry on with your normal activities. At other times, the drugs are given by an injection into a vein in the arm (intravenously). Many chemotherapy treatments can be given to you as an outpatient, although sometimes you may need a short stay in hospital.

The most common types of chemotherapy given for low-grade lymphomas are tablets called chlorambucil, or a drug called fludarabine. Fludarabine can be given as tablets or as a liquid into the vein.

A combination of chemotherapy drugs called **CVP** is also used. CVP includes the chemotherapy drugs:

cyclophosphamide®  
vincristine®,  
and prednisolone (a steroid).

A monoclonal antibody called rituximab is often given alongside CVP.

### ***High-grade lymphoma***

Chemotherapy for high-grade lymphomas is given into a vein (intravenously). Usually, a combination of several drugs is given over a few days and this is followed by a gap of a few weeks. This allows your body to recover from any side effects before the next treatment. Your treatment will probably last for several months and during this time you will have regular check-ups. Sometimes the chemotherapy is given once a week over a shorter time span, perhaps three to four months.

The most commonly used chemotherapy for high-grade lymphomas is a combination of four drugs called CHOP. CHOP is a combination of the chemotherapy drugs:

cyclophosphamide  
doxorubicin (doxorubicin hydrochloride)  
vincristine (Oncovin®)  
and prednisolone (a steroid).

A monoclonal antibody called rituximab is usually given alongside CHOP.

### ***Intrathecal chemotherapy***

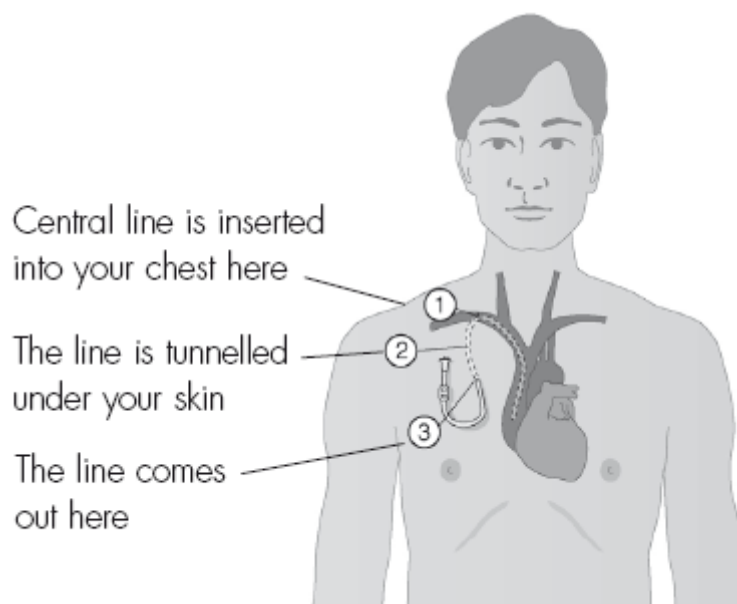
Some people with particular types of lymphoma have a lumbar puncture done at the start of chemotherapy. This is to check if there are lymphoma cells in the spinal fluid. If lymphoma cells are found, you will be advised to have chemotherapy directly into the spinal fluid on several occasions until the lymphoma cells are gone. Even if no lymphoma cells are found, your doctors may decide to give several doses of a chemotherapy drug directly into the spinal fluid to prevent lymphoma cells from growing there. Giving treatment in this way is known as intrathecal chemotherapy. Intrathecal treatment may be given as an outpatient, but sometimes it may mean an overnight stay in hospital.

### ***Central lines***

Some people having chemotherapy may find it easier to have a central line. A central line is a long tube made from silicone rubber that is inserted into a main vein in the chest. They are also called tunnelled central venous catheters and can be put in under local or general anaesthetic.



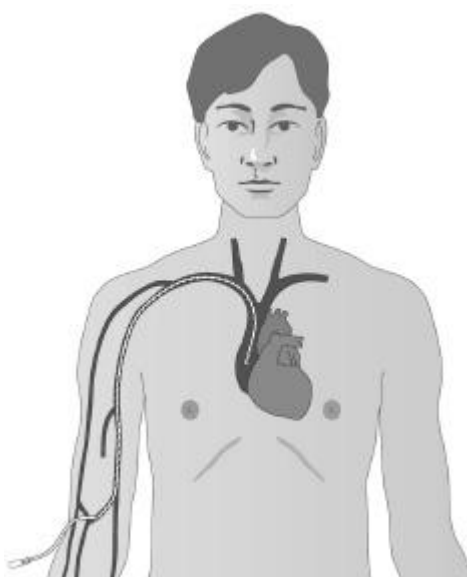
Chemotherapy and other drugs can be given through the line and blood samples can be drawn out with a syringe. The central line stays in throughout your treatment. Once your treatment is finished, the line is taken out. Usually this is easily done, using local anaesthetic if needed.



Position of a central line

### ***PICC Lines***

A PICC line (peripherally inserted central catheter) is like a central line, but is put into a vein in the bend of your arm instead of the chest. You can have a PICC line put in as an outpatient, using local anaesthetic. Your PICC line can stay in throughout your treatment and can be used to give drugs or take blood. Once you have finished your treatment, the PICC line is easily removed.

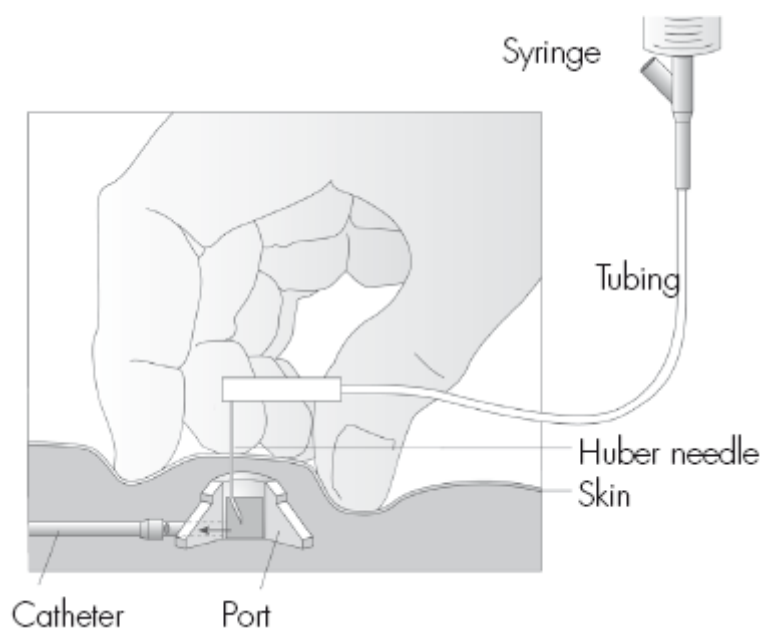


The PICC line is threaded through the vein until the end is near to your heart

### ***Implantable ports***

Some tubes end in small 'ports' that lie just under the skin of the chest: these are known as implantable ports (see diagram below). The port can be used to give chemotherapy and other

drugs, and also to take blood samples. You will be given either a local or a general anaesthetic before the port is inserted. Once your treatment is finished, the port is removed. Usually, this is easily done, using a local anaesthetic if necessary.



### ***Side effects of chemotherapy***

Chemotherapy can cause unpleasant side effects, but these can often be well controlled with medicines. Not all drugs cause the same side effects and some people may have very few side effects. Your doctor will tell you about any problems that your treatment may cause.

### **Lowered resistance to infections**

While the drugs are acting on the lymphoma cells in your body, they also temporarily reduce the number of normal white cells in your blood. When these cells are reduced you are more likely to get an infection and you may tire easily. During chemotherapy your blood will be tested regularly and, if necessary, you may be given antibiotics to treat any infection. Injections (growth factors) may also be given to stimulate the production of white blood cells by the bone marrow.

Contact your doctor or the hospital straight away if:

- your temperature goes above 38°C (100.5°F)
- you suddenly feel unwell (even with a normal temperature).

You will have a blood test before having more chemotherapy, to make sure that your cells have recovered. Occasionally your treatment may have to be delayed if your blood count is still low.

### **Anaemia**

If the level of red blood cells (haemoglobin) in your blood is low you will become very tired and lethargic. You may also become breathless. These are all symptoms of anaemia – a lack of haemoglobin in the blood.

Anaemia can be very successfully treated by blood transfusions. You will feel more energetic and the breathlessness will be eased.

### **Bruising and bleeding**

Platelets are a type of blood cell which help the blood to clot. If the number of platelets in your blood is low you will bruise easily and may bleed heavily from even minor cuts or grazes. Let your

doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, and bleeding gums. We have a booklet on platelet transfusions.

### **Feeling sick**

Some of the drugs used to treat NHL can make you feel or be sick (nausea and vomiting), but there are very effective anti-sickness drugs (anti-emetics) to prevent this. If the sickness is not controlled or continues, even with anti-sickness treatment, let your doctor know. They can prescribe other anti-sickness drugs which may be more effective.

### **Tiredness**

Chemotherapy affects people in different ways. Some people find they are able to lead a fairly normal life during their treatment, but many find they have to take things much more slowly. Tiredness can build up over a course of treatment, and if you have had a lot of chemotherapy, it can last for several months or more after your treatment has finished. Try to cut down on any unnecessary activities and ask your friends or family to help with jobs such as shopping and housework. Gentle exercise can sometimes help with the symptoms of fatigue.

### **Sore mouth**

Some chemotherapy drugs can make your mouth sore and cause small mouth ulcers. It is important to have regular mouthwashes to keep your mouth clean and the nurse will show you how to use these properly. Using a soft toothbrush can be helpful.

If you don't feel like eating during your treatment, you could try replacing some meals with nutritious drinks or a soft diet. You may find our booklet on eating problems helpful.

### **Hair loss**

Unfortunately, some chemotherapy drugs will make your hair fall out. People who lose their hair often wear wigs, hats or scarves. If you are being treated as an inpatient, or you are on income support, you can get a free wig from the NHS. If not, you can still get a subsidised wig from the hospital. Ask your doctor or the nurse about seeing a wig specialist. If your hair falls out it is important to protect your scalp from the sun. If you lose your hair, it will start to grow back within three to six months of finishing your treatment.

**Although they may be hard to bear at the time, these side effects will gradually disappear once your treatment is over.**

### ***Permanent side effects***

Chemotherapy can have long-term (permanent) side effects. Again, these will vary depending on the drugs you are treated with.

### **Infertility**

The most common permanent side effect is infertility (although not all chemotherapy drugs affect your fertility). Men may stop producing sperm, although they will continue to orgasm and ejaculate normally. Sperm banking can often be carried out before treatment.

Most women find that their periods stop or become irregular during treatment. They may go back to normal after treatment, but the closer you are to the age of your natural menopause, the more likely it is that chemotherapy will stop your periods permanently. If this happens, you can be given hormone replacement therapy. This will not give you back your fertility, but it helps with menopausal symptoms such as hot flushes, dry skin, vaginal dryness and a drop in sexual desire.

### **Other effects**

Some chemotherapy drugs may slightly affect the way that your heart works. With some drugs there is a small risk that they may cause another cancer many years later. This risk of long-term side effects has to be balanced against the benefit of the chemotherapy in curing or controlling the

lymphoma. If you are worried about the risk of long-term side effects it is helpful to discuss this with your doctor or specialist nurse.

## Steroid therapy for non-Hodgkin lymphoma

Steroids are drugs which are often given with chemotherapy to help treat lymphomas. They also help you to feel better and can reduce feelings of sickness due to chemotherapy.

### **Side effects**

Steroids as part of lymphoma treatment are usually only given for short periods of time and usually have few side effects. The side effects you may notice are:

- indigestion
- an increased appetite
- feeling very restless
- difficulty getting to sleep.

If you have to take steroids for some time, you may have some other temporary side effects, which can include:

- puffiness of the eyelids, hands, fingers and feet
- higher blood pressure
- a slightly higher risk of getting infections.

You may also have a higher level of sugar in the blood. If this happens to you, your doctor will prescribe medicines that you will need to take daily to bring your blood sugar level back to normal. You may have to do a simple daily test to check for sugar in your urine. The nurses will show you how to do this.

It is important to remember that all these side effects are temporary and will gradually disappear as the steroid dose is reduced.

## Monoclonal antibody therapy for NHL

Monoclonal antibodies are drugs that can recognise specific cells in the body. These drugs are designed to find a particular type of cancer cell, attach themselves to them and destroy them.

- Rituximab
- Other monoclonal antibodies

### **Rituximab**

A monoclonal antibody treatment called rituximab (Mabthera®) is used in the treatment of some types of non-Hodgkin lymphoma. It may be used on its own or in combination with chemotherapy.

Rituximab attaches to a protein called CD20 that is found on the surface of B lymphocytes, both normal and cancerous. Rituximab stimulates the body's natural defences to attack and destroy the lymphocytes. It attacks some healthy B lymphocytes (white blood cells) as well as the lymphoma cells, but the body can replace the healthy ones and the level of these cells in the blood returns to normal within a few months once the treatment has ended.

Rituximab is given as a drip (infusion) into a vein, and can be used in different ways. It is sometimes given in combination with CVP chemotherapy, as the first treatment for some types of low-grade NHL. It may also be given on its own as four, weekly sessions if low-grade NHL comes

back after previous treatment. If rituximab works well to treat low-grade NHL it is sometimes used, on its own, as maintenance therapy, for up to two years.

As treatment for high-grade NHL, rituximab is usually given alongside CHOP chemotherapy.

### ***Other monoclonal antibodies***

Some monoclonal antibodies have radioactive molecules attached to them, which give a dose of radiation directly to the cancer cells. Radioactive monoclonal antibodies that may be used to treat NHL include ibritumomab tixuetan (Zevalin®) and tositumomab (BEXXAR®).

Other monoclonal antibodies are being developed and you may be offered these as part of research trials. Some research trials use monoclonal antibodies in combination with chemotherapy.

Some people can have an allergic reaction to monoclonal antibodies, particularly with the first dose. This can cause a flu-like reaction, a drop in blood pressure or feelings of sickness. Because of this, the first dose is given slowly, over a number of hours. You may be given some other medicines first to make a reaction less likely. You are less likely to react to further doses.

## **Radiotherapy for non-Hodgkin lymphoma**

Radiotherapy treats cancer by using high-energy rays, which destroy the cancer cells, while doing as little harm as possible to normal cells.

How it is given  
 Planning radiotherapy  
 Side effects

### ***How it is given***

Radiotherapy treatment is directed at specific parts of the body and may be used when the lymphoma cells are contained in one or two areas of lymph nodes in the same part of the body (stage 1 or 2). It is often given along with chemotherapy.

The treatment is normally given as a series of short daily sessions. The treatments are usually given daily, Monday to Friday, with a rest at the weekend. The number of treatments will depend on the type and stage of the lymphoma, but the whole course of treatment will usually last a few weeks.

Each treatment takes from 10 to 15 minutes. Your doctor will discuss the treatment and possible side effects with you.

### ***Planning radiotherapy***

Radiotherapy has to be carefully planned to make sure that it is as effective as possible. On your first visit to the radiotherapy department, you will be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated. The treatment is planned by a clinical oncologist (a cancer specialist). Planning is a very important part of radiotherapy and may take a few visits.

The radiographer, who gives you your treatment, will draw marks on your skin to help position you accurately and to show where the rays are to be directed. These marks must stay throughout your treatment. Permanent marks (like tiny tattoos) may be used. These are tiny, and will only be done

with your permission. Some people need to have a mould made of the area being treated – this is to help you keep still during the treatment.

At the beginning of your treatment you will be given advice on how to look after your skin in the area being treated. Perfumed soaps, creams or deodorants may irritate the skin and should not be used during the treatment.

Before each session of radiotherapy, the radiographer will position you carefully on the couch, and make sure you are comfortable. During your treatment, which only takes a few minutes, you will be left alone in the room but you will be able to talk to the radiographer who will be watching you.

Radiotherapy is not painful but you do have to lie still for a few minutes while the treatment is being given.



A radiographer watches on a monitor while treatment is given

### **Side effects**

Radiotherapy will nearly always make people tired. Other side effects you have will depend on the part of your body being treated.

treatment to the abdomen can cause stomach upsets such as feeling sick (nausea), vomiting or diarrhoea.

treatment to the head can make your hair fall out in the treated area.

radiotherapy to the neck can make your mouth or throat sore and you may notice that some foods taste different from normal.

The side effects can be mild or more troublesome, depending on the part of the body being treated and the radiotherapy dose. Your radiotherapist will be able to advise you about what to expect and your doctor can prescribe medicines to help with side effects such as sickness or diarrhoea. Our booklet on eating problems has helpful tips on coping with eating problems caused by treatment.

Radiotherapy can have long-term (permanent) side effects. These are rare and, again, will vary depending on the part of the body treated. You can ask your specialist about possible long-term side effects.

We have a booklet on radiotherapy, which gives more details about this treatment and its side effects.

## Follow-up after treatment for non-Hodgkin lymphoma

After your treatment has finished, you will be asked to go back to the hospital for regular check-ups. To begin with, these may be every month but they will gradually take place less often. Your doctor will ask how you are feeling and examine you. You may have a blood test. From time to time, you may also have a CT scan, chest x-ray or ultrasound scan.

You should see your GP or hospital doctor if, between your follow-up visits, you have a symptom which:

- you cannot readily explain
- lasts more than a week
- is not getting better.

For people whose treatment is over apart from regular check-ups, our booklet, *adjusting to life after cancer treatment*, gives useful advice on how to keep healthy and adjust to life after treatment.

## If non-Hodgkin lymphoma comes back

For some people, treatment will completely cure their lymphoma. Other people, however, may find that their lymphoma comes back. If this happens, it may still be possible to give treatment in order to provide a further remission.

Even if this is not possible, treatment can be given to shrink the lymph nodes and control the disease to keep you well, often for long periods. Such treatment might be chemotherapy, radiotherapy, a combination of both, or a stem cell transplant.

- High-dose treatment with stem cell support (transplant)
- Transforming from low-grade to high-grade

### ***High-dose treatment with stem cell support (transplant)***

Some people may be offered treatment with very high doses of chemotherapy, sometimes combined with radiotherapy.

Your doctor will discuss with you whether this treatment is appropriate and possible in your case. High-dose chemotherapy is a very intensive treatment that needs to be given by doctors with experience of managing the side effects.

Before high-dose treatment can be considered, stem cells (the basic blood cells from which other cells develop) must be collected from your body at a time when you are well. This is called a stem cell harvest. The stem cells are then frozen and kept in storage until you have high-dose treatment.

**Harvesting** the stem cells involves giving you several injections of growth factors to increase the number of stem cells in your blood. The stem cells are then collected by a process in which blood is removed through a needle in your arm. The blood is then passed through a machine called a cell separator. The cells are separated out as the rest of your blood flows back in to you through another needle. Alternatively, stem cells can be collected from your bone marrow. For this, you will need to have a general anaesthetic.

High doses of chemotherapy destroy the bone marrow, where our blood cells are usually made. After the high-dose chemotherapy has been given, the stem cells are thawed and given back into your blood through a drip. The stem cells make their way to your bone marrow where they start to

produce blood cells. This can take a few weeks. You will be very prone to infection at this time so you are likely to need to stay in hospital.

In most cases, your own stem cells are collected and then given back to you after the high-dose chemotherapy. This is called an **autologous** transplant.

Some people may be given stem cells from another person (a donor) rather than using their own cells and this is called an **allogeneic** transplant.

Our booklet stem cell and bone marrow transplants gives more information on this treatment.

### ***Transforming from low-grade to high-grade***

Over time, some low-grade (indolent) lymphomas can become more aggressive (high-grade). This happens in about a third of all low-grade NHL and depends upon the type. It can take many years before an indolent lymphoma becomes high-grade. If indolent lymphoma transforms, it will need to be treated as a high-grade lymphoma.

Sometimes it is possible for both low-grade and high-grade NHL to be diagnosed in the same person, at the same time. If this happens the NHL is usually treated as high-grade.

## **How treatment for NHL might affect your fertility**

Unfortunately, some types of chemotherapy for non-Hodgkin lymphoma can cause infertility. Your doctor will talk to you about this in more detail before you start your treatment. If you have a partner, you may find it helpful to see the doctor together so you can both discuss any fears or worries. Some drugs do not cause infertility and these are being used more often than those that do. Unfortunately, the intensive chemotherapy and radiotherapy necessary before a stem cell transplant may be more likely to make you permanently infertile.

- Contraception
- Feelings about fertility
- Preserving fertility

### ***Contraception***

If your chemotherapy does make you infertile, it may not do so straight away. Because of this you may still be able to get pregnant, or father a child. You will normally be advised to avoid pregnancy during your chemotherapy treatment and for up to a year afterwards. To prevent this, you should use reliable contraception, such as a condom. It is important to remember that there are many couples who have had healthy babies following chemotherapy treatment – there is no increase in the risk of birth defects in children of people who have had treatment for cancer.

As your doctor knows the exact type of treatment you are having, they are the best person to answer your questions about fertility. Make a list of any questions you may have so you can be sure you are clear about your treatment.

### ***Feelings about fertility***

If chemotherapy does make you infertile, it can be very difficult to come to terms with the fact that you can't have children. You may feel that you have lost a part of your identity. Talking about your feelings with your partner, family or a close friend can help to clarify your thoughts and give the people close to you the chance to understand how you are feeling.



If it would be easier for you to talk to someone outside your immediate circle, you may find it helpful to talk to your nurse, social worker, our nurses or a trained counsellor.

### ***Preserving fertility***

Some people can preserve their fertility by storing sperm or fertilised (and in some situations, unfertilised) eggs. These procedures have to be done before you start treatment, but the eggs and sperm can be stored until you need them. It is important to bear in mind that some of the methods of collecting eggs or sperm can take quite a while. You may have to weigh up the benefits of having fertility preservation against the drawback of delaying your treatment.

### **Men**

If men have radiotherapy to the abdominal area, a lead shield may be used to protect the testes. If there is a risk of infertility it is usually possible for men to have sperm stored before starting treatment. Parents of teenage boys should also be aware of this so that, where possible, sperm can be stored for use in later years.

If you are infertile and would like to have a child, it may also be possible for your partner to become pregnant using donated sperm.

### **Women**

If women are to have radiotherapy to the abdomen it is sometimes possible to surgically move the ovaries out of the treatment area before the treatment starts.

It may be possible to store fertilised eggs with the chance of re-implanting them later. This may be worth considering if you and your partner want a child, and you are going to have chemotherapy that may make you infertile. Your treatment will need to be delayed for several weeks while the eggs are collected. Your specialist will be able to advise you about any potential risk in delaying treatment.

It is sometimes possible to store unfertilised eggs so that they can be fertilised and re-implanted when needed. However, this is much less successful than storing fertilised eggs and not widely available. Research is looking at whether it is possible to remove and store ovarian tissue, and re-implant it after your treatment has finished, but this is still experimental. If you are infertile, it may be possible to have infertility treatment (IVF) with donor eggs, so that you and your partner can have a child.

## **Research - clinical trials for NHL**

Cancer research trials are carried out to try to find new and better treatments for non-Hodgkin lymphoma. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side effects
- compare the effectiveness of drugs used for symptom control
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

### ***Taking part in a trial***

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

### ***Current trials***

There are a number of different trials for non-Hodgkin lymphoma. These include studies looking at chemotherapy schedules, the dose of radiotherapy, the use of rituximab and other monoclonal antibodies, and other biological treatments. There are different trials for different types of NHL.

The process of clinical trials is described in more detail in our booklet understanding cancer research trials.

### ***Blood and tumour samples***

Many blood samples and bone marrow or tumour biopsies may be taken to find out what is wrong with you. Most of these are needed to make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. Some samples may be frozen and stored for future use, when new research techniques become available.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

## **JASCAP resources**

### **Talking about your cancer**

Practical advice and guidance for cancer patients to help them communicate with family, friends, carers and health professionals about emotional and practical issues arising from a diagnosis of cancer and cancer treatment.

### **Talking to children about cancer**

Practical advice and guidance to help parents with cancer talk to their children about their cancer.

### **Talking to someone with cancer**

Practical advice and guidance for friends, carers and family members to help them talk to their friend or relative with cancer, and provide emotional and practical support.

***Note: JASCAP has booklets on each of the above subjects.***

## Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. \_\_\_\_\_

Answer \_\_\_\_\_

\_\_\_\_\_

2. \_\_\_\_\_

Answer \_\_\_\_\_

\_\_\_\_\_

3. \_\_\_\_\_

Answer \_\_\_\_\_

\_\_\_\_\_

4. \_\_\_\_\_

Answer \_\_\_\_\_

\_\_\_\_\_

5. \_\_\_\_\_

Answer \_\_\_\_\_

\_\_\_\_\_

## **JASCAP : We need your help**

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

### **Note for Reader**

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

# JASCAP

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS,  
C/O ABHAY BHAGAT & CO., OFFICE NO.4, "SHILPA",  
7<sup>TH</sup>. ROAD, PRABHAT COLONY,  
SANTACRUZ (East),  
MUMBAI - 400 055.  
PHONE: 91-22-2617 7543 & 91-22-2616 0007  
FAX: 91-22-2618 6162,  
e-mails: [pkrjascap@gmail.com](mailto:pkrjascap@gmail.com), [abhay@abhaybhagat.com](mailto:abhay@abhaybhagat.com)

AHMEDABAD: MR. D.K.GOSWAMY,  
1002, LABH, SHUKAN TOWER,  
NEAR JUDGES' BUNGALOWS,  
AHMEDABAD - 380 015.  
PHONE : 91-79-6522 4287. Mob : 93270 10529  
e-mail : [dkgoswamy@sify.com](mailto:dkgoswamy@sify.com)

BANGALORE: MS. SUPRIYA GOPI,  
455, I CROSS,  
HAL III STAGE,  
BANGALORE – 560 075  
PHONE : 91-80-2528 0309 .  
e-mail : [supriyakgopi@yahoo.co.in](mailto:supriyakgopi@yahoo.co.in)

HYDERABAD: MS. SUCHITA DINAHER & DR. M. DINAHER, M.D.,  
FLAT NO. G4, 1<sup>ST</sup>. FLOOR, "STERLING ELEGANZA",  
STREET NO.5, NEHRUNAGAR,  
SECUNDERABAD – 500 026.  
PHONE : 91-40-2780 7295.  
e-mail : [suchitadinaker@yahoo.co.in](mailto:suchitadinaker@yahoo.co.in)