



Treating Non Hodgkin's Lymphoma (NHL) - A Quick Guide

Contents

This is a brief summary of the information on 'Treating non Hodgkin's lymphoma' from CancerHelp UK. You will find more detailed information on the website.

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Staging non Hodgkin's lymphoma

Staging is important because your doctor uses the stage to work out the treatment you will need. There are 4 stages of non Hodgkin's lymphoma

- Stage 1 - you have one group of lymph nodes affected **or** lymphoma just in one organ of the body

- Stage 2 - you have 2 or more groups of lymph nodes affected. They are on the **same side** of your diaphragm
- Stage 3 - you have lymph nodes affected on **both sides** of the diaphragm
- Stage 4 - your lymphoma has spread outside the lymph nodes, for example, to the liver, bones or lungs

The letter B will be put after your stage if you have night sweats, a high temperature that comes and goes, or have lost a lot of weight over a short period of time and don't know why. The letter A will be put after the stage if you do **not** have any of these symptoms. Your doctor needs to know about your symptoms because the treatment is sometimes different for people with B symptoms.

Stages of NHL made simple

In practice, to work out what treatment you need, doctors classify NHL as either limited or advanced. Limited means stage 1 or 2, type A, and with all tumours less than 10cm across. Advanced means stage 3 or 4, or type B, or any tumour more than 10 cm across.



Statistics and outlook for non Hodgkin's lymphoma

Outlook means your chances of getting better. Your doctor may call this your prognosis. The likely outcome of non Hodgkin's lymphoma depends partly on how advanced the cancer is when it is diagnosed (the stage). But the type of lymphoma and whether your lymphoma is low or high grade is also very important.

On CancerHelp UK, we have quite detailed information about the likely outcome of different stages and types of NHL. The statistics we use are taken from a variety of sources, including the opinions and experience of the experts who check every section of CancerHelp UK. They are intended as a general guide only. For the more complete picture in your case, you'd have to speak to your own specialist.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. Many individual factors affect your treatment and your outlook. Outcomes for patients with most types of lymphoma have improved steadily over time. Because of the way they are collected statistics tend to show these improvements some years later.

Types of treatment for non Hodgkin's lymphoma

When non Hodgkin's lymphoma is diagnosed a team of doctors and other professionals work together to decide on the best treatment for each person. The main types of treatment for NHL are chemotherapy, radiotherapy, and biological therapy.

Some people need only one type of treatment and others need more than one.

Your doctors need to know several things to be able to decide which treatment you need, including

- The type and grade of NHL you have
- The stage of NHL you have
- Your general health
- Your age

There are many different types of non Hodgkin's lymphoma. Your doctor can tell which type you have by looking at the cells under a microscope. The different types are grouped together depending on whether they tend to be faster or slower growing. This is called the grade of NHL. Non Hodgkin's lymphomas can be low grade, which are slow growing or high grade, which are faster growing.

Treatment for limited low grade non Hodgkin's lymphoma

You are most likely to have radiotherapy to the affected lymph nodes. For many people this treatment can cure their non Hodgkin's lymphoma.

Treatment for advanced low grade NHL

With advanced low grade NHL, your doctor is usually trying to control the disease rather than cure it. It can often be controlled for several years.

If you are having symptoms or have enlarged lymph nodes, your doctor will give you a combination of treatment called R-CVP. This is the most common treatment for advanced follicular lymphoma. You will have chemotherapy with the drugs cyclophosphamide and vincristine, and the steroid prednisolone with a type of monoclonal antibody called rituximab. If you



are elderly you may have chlorambucil chemotherapy tablets to take at home.

Some research is looking into maintenance, or consolidation, treatment for low grade NHL. This means treatment you have when the lymphoma has gone to try to stop it coming back for as long as possible. This type of treatment is also known as consolidation. The drugs being tested are biological therapies.

Lymphoma tends to come back after a period of time and you will need more treatment. The next lot of treatment you have is called 'second line' treatment. There are a lot of choices. Your doctor decides your treatment by looking at your previous responses to treatment, how quickly they want the treatment to work and convenience for you.

Treatment for high grade non Hodgkin's lymphoma

Treatment for high grade non Hodgkin's lymphoma will depend on which type of lymphoma you have and on whether you have limited or advanced lymphoma.

If you have limited high grade NHL, you may just have radiotherapy to lymph nodes affected by non Hodgkin's lymphoma. Many doctors are now giving short courses of chemotherapy and monoclonal antibody treatment as well as radiotherapy. This is because they think the chemotherapy and antibody treatment will increase the chance of curing the lymphoma.

If you have advanced high grade NHL, you will probably have chemotherapy treatment with 3 or 4 different drugs, or more, and a monoclonal antibody. The exact choice of treatment depends on which type of high

grade NHL you have. If you have advanced high grade diffuse B cell lymphoma, you will have CHOP chemotherapy together with a monoclonal antibody called rituximab. This is called R-CHOP.

For some types of NHL, you may have chemotherapy into the fluid around your spine to prevent lymphoma cells spreading to the brain. Usually, you will be given a drug called methotrexate. High dose methotrexate injections into the bloodstream, instead of into the spine, can sometimes replace the need for injections into the spinal fluid.

Some patients with aggressive types of high grade non Hodgkin's lymphoma have very intensive high dose chemotherapy with bone marrow or stem cell transplant.

Surgery for non Hodgkin's lymphoma

Surgery is not really used as a treatment for NHL. This is because even the best surgeon is not able to accurately identify all areas of lymphoma and remove them. And because these days chemotherapy usually works well. But you may have an operation to remove a lymph node for testing (biopsy).

For a lymph node biopsy your doctor removes a lymph node while you are under anaesthetic and sends it to the laboratory. This is a very small operation. These days doctors sometimes use ultrasound or other types of scans to biopsy a lymph node without you having an anaesthetic.

Removing your spleen

If you have a very rare type of NHL called splenic marginal zone lymphoma, doctors may remove the spleen. But this type of operation is not very common. Occasionally



the spleen may also be removed in other types of NHL. You will be more at risk of infection without a spleen. You will have to take antibiotics for the rest of your life to help stop infection. You should carry a card saying you have no spleen in case of medical emergencies.

About radiotherapy for non Hodgkin's lymphoma

Radiotherapy uses high energy rays to kill cancer cells. Radiotherapy is often used as a **local** treatment. It is used when there are lymphoma cells in one or two areas of lymph nodes in one part of the body (stage 1 or 2). You may have radiotherapy with chemotherapy if there is a lot of lymphoma. Or after chemotherapy to help stop the lymphoma from coming back.

You usually have radiotherapy treatment once a day from Monday to Friday, with a rest over the weekend. The length of the treatment will depend on the type and size of your lymphoma. Each treatment only takes a few minutes. You cannot feel it and it does not make you radioactive. There is no risk to your family when you return home.

Planning your treatment

On your first visit, you lie under a large machine called a simulator. This takes normal X-rays. The doctor uses it to work out exactly where to give the treatment. The doctor will make marks on your skin that the radiographer will use to line up the radiotherapy machine when you have your treatment.

Side effects

Radiotherapy has two main side effects. It can cause red, sore skin in the area being treated. And it makes you very tired. If

you are having radiotherapy to your brain, as part of a bone marrow or stem cell transplant, you may have extreme tiredness. Other radiotherapy side effects vary, depending on the part of the body being treated.

There is more information in the main 'radiotherapy' section of CancerHelp UK.

What to ask your doctor about radiotherapy for non Hodgkin's lymphoma

- Why are you recommending radiotherapy for me?
- How long will the course of treatment last?
- Where will I have the treatment?
- How will I get to the hospital and back?
- Is it possible to have help paying my fares?
- Are there any other treatment options?
- Will I have to have any other treatment?
- What are the side effects likely to be?
- Can I do anything to help prevent the side effects?
- Will I be able to work during the treatment period?
- How should I look after my skin?
- Will I have difficulties with eating and drinking? If so, what can I do about my diet?
- Will any of my hair fall out? If so, when will my hair grow back?
- Are there likely to be any long term side effects?

About chemotherapy for non Hodgkin's lymphoma

Chemotherapy uses anti-cancer or 'cytotoxic' drugs to destroy cancer cells. As



they circulate in the blood, they can reach cancer cells in almost all parts of your body. They can work in many different ways.

Chemotherapy for low grade lymphomas

For low grade lymphomas you may have chemotherapy tablets to take at home from time to time. Lymphoma is often treated with a combination of chemotherapy drugs. In particular situations, doctors may suggest very intensive chemotherapy with a bone marrow or stem cell transplant. This is still very new treatment for low grade lymphoma and is normally used after chemotherapy drugs have been tried.

Chemotherapy for high grade lymphomas

Most high grade lymphomas are treated with a combination of several chemotherapy drugs and a type of drug called a monoclonal antibody. This treatment usually lasts for several months. The type of chemotherapy used depends on a number of factors including the exact type of lymphoma, the stage of the lymphoma and whether it has been treated before.

Chemotherapy to prevent spread to the brain

In certain situations, your doctor may want you to have treatment to prevent lymphoma spreading to your brain. The most common way of giving this treatment is to have injections of a drug called methotrexate into the fluid around your spine.

Chemotherapy and side effects for non Hodgkin's lymphoma

Many different drugs are used to treat lymphoma. Your nurse or doctor will give

you written information about the drugs you are having.

All chemotherapy drugs have side effects. But they affect people in different ways. Some people may have very few side effects. Side effects depend on the drugs you have, the dose and your own individual reaction to treatment. Common side effects include

- A fall in the number of blood cells
- Feeling sick
- Diarrhoea
- Sore mouth and mouth ulcers
- Hair loss or thinning
- Feeling tired and run down

CancerHelp UK has details about the different chemotherapy drugs and combinations used to treat NHL.

Long term side effects

Chemotherapy can sometimes cause permanent side effects. These include infertility, and an increased risk of heart problems or a second cancer in the future. Your doctor or specialist nurse can tell you more about this.

What to ask your doctor about chemotherapy for non Hodgkin's lymphoma

- Why are you recommending chemotherapy for me?
- What are the risks and benefits of this treatment?
- How often will I have to come to the hospital?
- Can I have the treatment as an out patient or will I have to stay in hospital?
- How long will the course of chemotherapy be?



- Is there any other choice of treatment?
- What are the side effects likely to be?
- What can I do to reduce the side effects?
- Can you arrange a wig for me on the NHS?
- Will I still be able to have children after the treatment?
- Will the treatment cause an early menopause? If so, how will you treat this?
- Is there any way I can keep my fertility?
- Can I have eggs or embryos frozen before my chemotherapy?
- Can you arrange sperm banking for me before I start my chemotherapy?
- Are there any new drugs on clinical trial that may help me?

Stem cell transplants for non Hodgkin's lymphoma

Stem cells are very early blood cells. Red cells, white cells and platelets can all develop from them. They are normally found in the bone marrow, but doctors have ways of getting them into the bloodstream so they can be collected more easily.

What is a stem cell transplant?

Stem cell transplant is a way of giving very high doses of chemotherapy, sometimes with radiotherapy. High doses of chemotherapy drugs and radiotherapy kill off your bone marrow and any remaining NHL cells. This means you cannot make any new blood cells. So doctors take some stem cells from your blood **before** you have your chemotherapy and freeze them.

After you have had the chemotherapy, you have your stored stem cells back through a drip. Then you can make the blood cells

you need again. This is called an autologous stem cell transplant.

Collecting the stem cells

Collecting the stem cells takes 3 or 4 hours each time. A drip is put into each of your arms and attached to a machine. Your blood passes out of one drip, through the machine and back into your body through the other drip. The machine filters the stem cells out of your blood.

The stem cells are frozen until you are ready to have them back. This will be after all your high dose chemotherapy is finished.

Bone marrow transplants for non Hodgkin's lymphoma

Bone marrow transplants are similar to stem cell transplants. They are a way of giving very high dose chemotherapy, sometimes with radiotherapy, to try to cure some types of cancer. These days more people have stem cell transplants. But you might have a bone marrow transplant if collecting stem cells is difficult.

The bone marrow is the spongy substance inside your bones which makes all your blood cells. High doses of chemotherapy drugs kill off your bone marrow and any remaining NHL cells. This means you cannot make any blood cells. So doctors or specialist nurses can take out some of your bone marrow before you have the chemotherapy and freeze it. This is called a bone marrow harvest.

After you have had the chemotherapy, you have your bone marrow back through a drip. Then you can make the blood cells you need again. This is called an autologous bone marrow transplant. You may have bone marrow donated by another person



(usually a brother or sister). This is called an allogeneic transplant.

Having a bone marrow harvest

To have marrow taken, you have a general anaesthetic. The doctor puts a needle through the skin into your hip bone. They suck out the marrow through the needle into a syringe. Occasionally, the doctor uses the breast bone as well. When you wake up you will probably feel very sore and bruised. Your doctor will give you some painkillers to take.

After your marrow or stem cell harvest

Having high dose chemotherapy

After your stem cell collection you will have high dose chemotherapy to kill any non Hodgkin's lymphoma cells that are left in your body. You may have radiotherapy as well as chemotherapy.

You will have your chemotherapy through a central line. This means you don't have to have any injections. You can have other drugs through the tube, for example anti-sickness drugs. And you can have blood taken from the line for blood tests.

You have high dose chemotherapy over about 5 or 6 days. It depends which combination of drugs you have. If you are going to have radiotherapy, you are most likely to have it just before the bone marrow or blood cells are given back to you.

Having your stem cells back

After you have finished all your treatment, you have your stem (or bone marrow) cells back. They are given through a drip. The cells find their own way back into your

bones and start to grow again. Soon they will make new blood cells for you.

When you have high dose chemotherapy you are at risk of picking up infections. You may have a single room in the hospital ward, to help protect you from infection. You stay in the single room until your bone marrow has started to make blood cells again and your blood counts have come up. This can take a few weeks. You can have visitors, but your nurses may suggest that you only have one or two each day.

Side effects of bone marrow or stem cell transplants for non Hodgkin's lymphoma

The side effects after transplants are much the same as when you have chemotherapy. But because you have higher doses, the side effects can be more severe. You may have additional side effects if you have radiotherapy as well. The main side effects of high dose chemotherapy are

- Risk of infection
- Drop in red blood cells (anaemia)
- Risk of bleeding
- Sickness and diarrhoea
- Sore mouth
- Difficulty eating and drinking
- Feeling tired and run down

Side effects are at their worst just after your transplant, and for a couple of weeks afterwards. When your blood counts start to rise you will start to feel better. You can have medicines to control sickness and diarrhoea.

You will have to take special precautions against infection. Even with precautions, most people do get an infection at some point and have to have antibiotics.



CancerHelp UK has more information about the side effects of high dose chemotherapy and radiotherapy.

What to ask your doctor about bone marrow or stem cell transplants for non Hodgkin's lymphoma

- Why are you suggesting a transplant for me?
- What sort of transplant will I have?
- Will you use stem cells or bone marrow?
- What are the risks and benefits of this treatment?
- Are there any other treatment options?
- Where will I have my transplant?
- Will I have to have chemotherapy and radiotherapy?
- How long will I be in hospital?
- Will I need to be in isolation and for how long?
- What are the side effects of this treatment?
- What are the long term side effects?
- Will this transplant cure my non Hodgkin's lymphoma?
- Will I be able to go back to work after this treatment?
- Will I still be able to have children after the transplant?
- Will the treatment cause an early menopause? If so, how will you treat this?
- Is it possible for me to have eggs or embryos frozen before I start treatment?
- Can you arrange sperm banking for me before I start my treatment?

Biological therapy for non Hodgkin's lymphoma

What are monoclonal antibodies?

There are several different types of biological therapies. The type used most often in lymphoma is a monoclonal antibody. Monoclonal antibodies (MABs) are proteins made in the laboratory that target the cells of particular types of cancer. A MAB called Rituximab is now commonly used to treat some types of lymphoma. It is also called Mabthera or Rituxan.

Who can be treated

Rituximab is part of standard treatment for high grade diffuse B cell lymphoma. Rituximab is also part of standard treatment for low grade follicular NHL that needs treatment.

Having the treatment

You have rituximab through a drip (infusion). You may have to stay in hospital overnight for your first treatment. The number of doses of rituximab and how often you have it depend on your type of lymphoma, and whether you are having it with other drugs.

Side effects

During the infusion, you may have fever, chills and shivering, feel sick, or have an itchy rash, or headache. A small number of people treated will also have wheezing and a drop in blood pressure. But you will be monitored closely by the nurse looking after you.

Steroid therapy for non Hodgkin's lymphoma

Steroids are substances made naturally in the body. They can also be made artificially and used as drugs.



How are steroids used in NHL?

In non Hodgkin's lymphoma you are likely to have steroids along with your chemotherapy drugs. Doctors have found that the treatment is more successful when you take steroids with your chemotherapy.

Side effects

Because you will not be taking the steroids for very long without a break, you are not likely to have bad side effects from them. But there are a few side effects you may notice. These can include having a bigger appetite, having more energy, difficulty sleeping, indigestion, and feeling irritable or low. Any side effects will go away when you stop taking the steroids.

If you have been taking steroids for some time you may notice some swelling in your hands, feet or eyelids. You may also put on weight. These symptoms are caused by extra fluid in your body due to the steroids.

You may be asked to test your urine for sugar. Steroids can change the way your body handles sugar. This change is temporary. It will stop when you stop having steroids.

Taking steroids also puts you at increased risk of infection. Your doctor will also check your blood pressure in case the steroids make it high.

It is important for any doctor treating you for any reason to know you are taking steroids. So your doctor will give you a card to carry to say you are taking steroids.

Treatment if non Hodgkin's lymphoma comes back

Many people with non Hodgkin's lymphoma will be cured. But your doctor

will not know straight away whether your lymphoma will come back or not. Some people find that their lymphoma comes back some time after treatment. If this happens to you, it may still be possible for your doctor to cure your NHL.

Even if your lymphoma cannot be cured, your doctor will be able to give you some treatment to control it. This may keep you well for long periods at a time. The treatments used for non Hodgkin's lymphoma that has come back are the same treatments that can be used when it is first diagnosed. These are

- Radiotherapy
- Chemotherapy
- Stem cell transplant
- Bone marrow transplant
- Monoclonal antibody treatment

You may be asked to have more intensive treatment than you had at first.

Suggestion - It can be very hard to cope with the news that your cancer has come back. Even if your doctor still hopes to cure you. You may want to think about having counselling. A trained counsellor can help you to talk about your fears and worries. And sometimes it feels easier to talk to someone outside your family and friends. There is more about counselling in the 'coping with cancer' section of CancerHelp UK.

Follow up for non Hodgkin's lymphoma

How often will I need check ups?

How often you need check ups depends on your type of NHL and what treatment you had. If you have just finished treatment



they will be more frequent. If all is well you will go less and less often. And if you are in a long term remission then your appointments may only be once a year.

What tests will be done?

Your doctor will examine you and you will probably have blood tests at each appointment. Sometimes you will have an X-ray or scan. Your doctor will ask how you are feeling and whether you have any new symptoms.

It is important to remember that if you are worried or notice any new symptoms between appointments let your doctor or nurse specialist know straight away. You don't have to wait until the next appointment.

Feeling worried about your check ups

Many people find their check ups quite worrying. They can bring back all the worry about having cancer. You may find it helpful to tell someone close to you how you are feeling. Or the Lymphoma Association may be able to put you in touch with other people who have had lymphoma. It is quite common nowadays for people to have counselling after cancer treatment. To find out more about counselling, look in the 'coping with cancer' section of CancerHelp UK.

Non Hodgkin's lymphoma research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to test are they tested in people, in clinical trials.

Researchers are looking into chemotherapy, radiotherapy doses, biological therapies, transplants, retinoids (substances that are related to vitamin A) and finding remaining lymphoma cells after treatment.

What to ask your doctor about treatment for non Hodgkin's lymphoma

- What type of non Hodgkin's lymphoma do I have?
- What can you tell me about the grade of my lymphoma?
- What stage is my lymphoma?
- What sort of treatment do I need?
- What is the aim of the treatment - to cure my lymphoma or control it?
- Is there a choice of treatments?
- How long will the treatment last?
- Will I have to have any surgery?
- Will I need to take steroids as part of my treatment?
- What side effects should I look out for?
- Could you arrange for me to have a second opinion?
- How often will you want to see me after my treatment is finished?
- What will happen at these follow up appointments?
- What should I do if I am worried between appointments?
- Will I be able to have more treatment if my lymphoma comes back?
- Is biological therapy treatment suitable for my type of lymphoma?



More information

For more information about non Hodgkin's lymphoma (NHL), visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in May 2011.

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