

# A Young Person's Guide to Lymphoma

## This book is for you...

...If you are a young person who has lymphoma. It gives information about lymphoma and how it is treated. It also covers ways you can look after yourself, and how you may feel.

## It is divided into sections

You don't need to read them in order. Besides information, a section may contain questions and answers; quotes from young people; hints and tips.

## Young people who have lymphoma are as different from each other as young people who do not

So, you may find some things in this booklet very helpful and others not at all. What you find useful could change as you go through treatment. You may want to show this to your friends and family so they have some idea of what is going on in your life at the moment.



# About Lymphoma

## *Did I catch lymphoma from someone?*

No, you cannot catch lymphoma.  
You can't give it to anyone else either.

## *Do I have lymphoma because of something I've eaten or drunk?*

There is no reason to link diet with developing lymphoma.

## *Is it something I've done that's given me lymphoma?*

Nothing you have done, or that other people have said or done has caused it.

## *Well, then, why me?*

At the moment, no-one can say why you have developed lymphoma. No-one can say why anyone develops lymphoma.

## *What is lymphoma?*

It is a type of cancer. Cancer occurs when cells are out of control. The cells don't respond normally to messages from the rest of the body. They divide when they don't need to and then there are too many. This causes a problem. In lymphoma the cells affected are white blood cells which travel around the body in **lymph**.

## *What is lymph?*

**Lymph** is a clear fluid that contains white blood cells, called **lymphocytes**. The body uses lymphocytes to fight infection. The lymphocytes are mainly found in the lymph nodes, but circulate around the body in both the blood stream and the **lymphatics**.

# The Lymphatic System

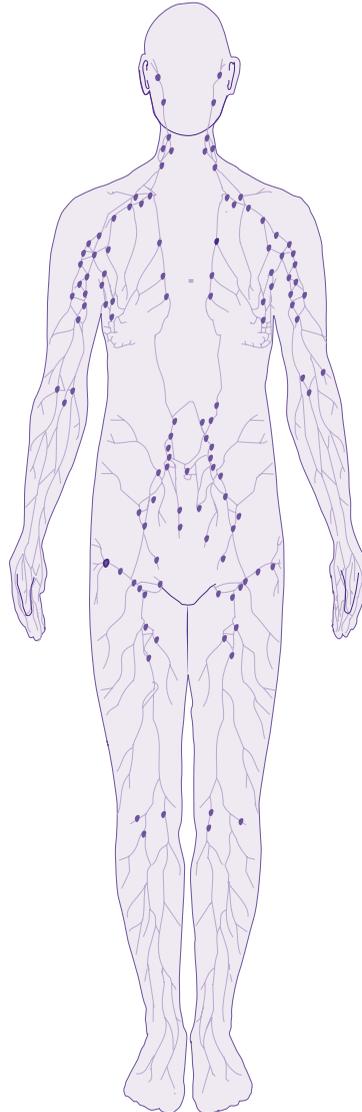
Lymph goes all round the body travelling in very narrow tubes called **lymphatics**.

The lymphatic system does not have its own pump. It depends on pressure from the blood system, and the massaging effect of muscles.

Around the body lymphoid cells gather in **nodes or glands**. For example, in the past you may have noticed lumps in your neck when you have been ill. These are enlarged lymph nodes that have been doing overtime battling against infection.

There are groups of lymph nodes in different parts of the body. You can see from the diagram where these groups are and the lymphatics connecting them.

Wherever there is lymphoid tissue it is possible to develop lymphoma.



# Tests

## Biopsy

A **biopsy** is a small operation to remove a gland or a piece of a lump. It is looked at under a microscope to see exactly which cells are involved. You may already have had a biopsy of a lymph node, as this is the main way of confirming suspected lymphoma.

The most suitable treatment for you is chosen depending on the result of the biopsy.

You will probably not get the results from the biopsy straight away. It is quite a complicated laboratory procedure. Nobody finds waiting easy, but it is important to know what type of lymphoma you have, so that you can have the right treatment.

## Scans

### *Why am I going to have a scan?*

Scans are needed because a lot of the lymph glands are deep within the body and can't be felt from the outside. A scan will also show if other parts of the body are affected.



There are different types of scan.

A **CT (Computerised Tomography)** scan uses a computer to analyse X-ray pictures of your body taken from lots of different angles. It builds up a 3-D view.

An **MRI (Magnetic Resonance Imaging)** scan builds up a similar 3-D picture by measuring the change in magnetic waves as they pass through your body.

An **ultrasound** scan uses high-energy sound waves which 'bounce off' any lumps in your body.

Again you will probably not get the scan results for a little while. They have to be carefully prepared and analysed.

Scan results show exactly where the lymphoma is, and are important in choosing the best treatment.

Scans do not hurt. You may be asked to drink some liquid. It's not too bad, but you certainly wouldn't ask for it in a pub!

Scans may take up to an hour. The machinery is large and can be noisy. You may be asked to lie still for quite a long time.

If you know you are going to have a scan, you could ask to visit beforehand, so you know what to expect.

Talk to someone who has had one.

## Bone marrow test

This may be needed to see if there are lymphoma cells in the bone marrow. A small sample of bone marrow is taken, usually from the pelvis. A local anaesthetic is used and you may be offered a sedative. You may be sore for a while after.

## Blood tests

You will need a lot of blood tests. Blood for testing is often taken from a vein in the arm, using a needle. If you have a **central** or **Hickman line**, blood may be taken from there. Central lines are explained in the chemotherapy section. Blood cells are created in the bone marrow. The cells in your bone marrow divide rapidly to produce new blood cells.

Chemotherapy and radiotherapy are designed to attack dividing cells. Chemotherapy kills blood cells in the bone marrow as well as lymphoma cells.

The main types of blood cell are described in the table opposite. Regular blood tests are needed to make sure you still have enough cells of each type.

## Lumbar puncture

Sometimes lymphoma can get into the fluid that surrounds the spinal cord and brain.

This fluid is called cerebrospinal fluid (CSF). It is collected from the space between two of the bones in the lower part of the spine, using a needle and syringe. A local anaesthetic is used first.

### *Are there any problems?*

Some people have a headache afterwards.

To avoid a headache – lie flat for a few hours afterwards.

Drink plenty of water.

	WHITE CELLS	RED CELLS	PLATELETS
MEDICAL NAME	Neutrophils Lymphocytes Monocytes	Erythrocytes	Platelets
WHAT THE CELLS DO	Fight infection	Carry oxygen	Stop bleeding
NAME OF SHORTAGE	Neutropaenia	Anaemia	Thrombocytopenia
NORMAL COUNT	Total white cells: 4-11 ( $\times 10^9/l$ )  Neutrophils: 2-6 ( $\times 10^9/l$ )	12-14 (g/dl)	150-400 ( $\times 10^9/l$ )
SHORTAGE MAY MEAN	Getting infections	Being pale, tired, breathless, cold, dizzy and having headaches	Bruising easily Bleeding longer Bleeding nose and gums Blood in urine
ACTION	Antibiotics. Put off treatment till count is normal again	Red cell transfusion	Platelet transfusion

# Diagnosis

After all the test results have been looked at you will know what type of lymphoma you have, and where it is in your body.

There are two main types: Hodgkin's disease (HD) and non Hodgkin's lymphoma (NHL).

Treatment of both types has improved enormously recently. Many young people are completely cured.

A lot of books are very out of date. A lot of statistics are general. The best people for you to talk to about your lymphoma are the people looking after you. What they tell you will apply to you.

## *What's the difference between Hodgkin's disease and non Hodgkin's lymphoma?*

In Hodgkin's disease the biopsy contains a type of cell called a Reed-Sternberg cell. This type of cell is not present in non Hodgkin's lymphoma. There are quite a lot of different NHL types.

## *Is the treatment the same?*

All lymphomas in young people are treated either by radiotherapy or chemotherapy. Sometimes both are given. The treatment you are given depends on your exact diagnosis.

Sometimes people worry if their treatment is different to another person's. Please don't, your treatment is especially designed for you.

*I've heard about side effects of treatment.  
What exactly is a side effect?*

A side effect occurs when a drug or treatment affects other things in the body, not just the problem it is aimed at. The chemotherapy and radiotherapy treatment for lymphoma may lead to side effects.

## Staging

Staging is a way of describing the spread of lymphoma. It will be used to help decide on your treatment.

*I have Hodgkin's disease 3A, what does that mean?*

The numbers and letters are used to show which parts of the body are affected, and what problems the lymphoma is causing. 3 means that lymph nodes in both the upper and lower body are affected. A means that you don't have major symptoms.

Stage 1	One group of lymph nodes has lymphoma
Stage 2	Two or more groups of lymph nodes have lymphoma. These groups are either above <u>or</u> below the diaphragm
Stage 3	Two or more groups of lymph nodes have lymphoma. These groups are above <u>and</u> below the diaphragm
Stage 4	Lymphoma is in other parts of the body as well as the nodes

A	B
You may not be feeling great, but you haven't got any of the B symptoms	Loss of weight – more than a tenth of normal weight
	High fever
	Drenching sweats at night
	Severe tiredness
	Loss of appetite

# Radiotherapy

## How it works

Radiotherapy uses powerful X-rays.

These are pointed at the lymphoma cells to destroy them.

The beam of X-rays has to be carefully positioned so that it gets all the lymphoma cells, but as few good cells as possible.

To do this the machinery has to be set up for you.

Various marks will be made on your skin with a special marker pen.

This makes sure that exactly the right area is treated.

Other parts of your body may be protected with special metal sheets which don't let X-rays through.

If you are having treatment to the head or neck, a special metal helmet will be made for you.

## *How long is a treatment?*

It normally lasts a few minutes.

A treatment doesn't hurt.

## *Will I be radioactive?*

No. You are not radioactive either during a treatment, or afterwards.



## *How often will I have radiotherapy?*

You will normally have one treatment a day. The number of treatments varies for different people. Usually treatments are daily for 2-6 weeks – not at weekends.

Everyone reacts in their own way to treatment. You may want to read about side effects now. Or you may prefer to wait and see what happens to you – if so, look at the Contents page again.

## Side effects

Radiotherapy can make you feel tired just after a treatment. Tiredness also builds up over time.

You may still feel tired for a while even when all your treatments are finished.

You may feel a bit sick, but it usually goes away quickly.

Your skin may be very tender, rather like sunburn. The hospital staff will tell you how to look after your skin. They may give you special cream.

Hair will be lost if the X-rays enter or exit your body through a hairy part of your skin.

You may get either diarrhoea or constipation if you are having radiotherapy to the abdomen. Sickness may be a problem if your abdomen is being treated.

If your throat or neck is treated your mouth may be dry or sore. You may have difficulty swallowing.

*"After I got home my Mum lit the living room fire, and I lay on the sofa under my duvet and slept for a couple of hours."*

Cover sore areas when you go out to protect them from sun and wind. Use sun block cream if it is recommended.

If you feel sick - *tell someone*. There are anti-sickness drugs.  
See Nausea hints, page 21.

If you have a dry, sore throat, drink regularly. Eat soft food.  
*Tell someone*. There are mouthwashes and sprays that can help.  
See Mouth care hints, page 19.

If you have diarrhoea, drink lots. *Tell someone*.  
See Diarrhoea hints, page 23.

# Chemotherapy

## How it works

The aim of chemotherapy is to destroy all the lymphoma cells in your body.

To do this a combination of drugs is chosen – this is sometimes called a '**cocktail**'. The choice of drugs depends on the type of lymphoma you have, where it is, your age etc.

How much of each drug you are given, and how often, is called the **treatment regimen**. Regimens have names usually made up from the first letters of the drugs involved.

### *Why do I have a mixture of drugs?*

The drugs in the cocktail work in different ways. For example, one drug may stop nourishment getting into lymphoma cells so that existing cells die. Another drug interferes with the lymphoma cells when they are on the point of dividing so they cannot increase in number.

### *I heard I'm going to have steroids. Will I get big muscles?*

The steroids used to treat lymphoma are not the same as anabolic steroids which are banned from sport. Your steroid treatment may increase your appetite and make you put on weight temporarily. You will be given a blue 'steroid card' which you should carry for about two years.

## *What is a stem cell transplant?*

Sometimes it is necessary to give an extra large amount of chemotherapy drugs. This means that the bone marrow takes much longer to start making blood cells again. So, before the chemotherapy is given, stem cells are collected from your blood. They are given back to you by transfusion after chemotherapy and they swim back to the marrow (unbelievable!).

## *What is a stem cell?*

It is a blood cell which is at an early stage of development. The body hasn't yet decided whether it is going to be a red, white, or platelet cell. Stem cells are very useful after high dose chemotherapy. They are put back into the blood stream and the body turns them into whatever cells it most needs.

## **How chemotherapy is given**

Chemotherapy drugs are often prepared in liquid form. They may be injected or dripped from a plastic bag into a vein in the arm using a narrow tube and a needle. This can take an hour or so. Sometimes a tube is put into a larger vein via a small hole in the chest. This is a minor operation.

The tube, or line, stays there throughout your treatment, which may be 3 to 6 months. This is known as a **Hickman** or **central line**. The hospital staff will discuss the method they plan to use. If you have any questions, just ask.

Other medicines may be given as pills, or liquid to swallow.

Everyone reacts in their own way to treatment.

You may want to read about side effects now. Or you may prefer to wait and see what happens to you - if so, look at the Contents page again.

## Hair loss

### *Will I lose my hair?*

Most probably, yes. The drugs used to kill the lymphoma cells will also kill other fast-growing cells such as hair cells.



### *Will it all fall out?*

Most people lose all their hair. For others it goes very thin on top, or may fall out in patches. The hair that remains may be weak.

### *When will it start to come out?*

Usually about 2 to 3 weeks after your first chemotherapy treatment.

### *Will it grow back?*

Yes. It may not be exactly the same. Sometimes hair grows thicker, wavier or a different colour.

### *How long will it take to grow again?*

It grows at the same rate as before. This means that between 3 to 6 months after treatment has stopped you will have a full head of new hair.

### *What about a wig?*

Some people choose to have a wig. A wig will not interfere with the growth of your new hair.

### *Are they expensive?*

You may be entitled to a wig on the National Health Service.



## What about other hair on my body?

Other body hair is not as fast growing as the hair on your head. It may or may not be affected. It will depend on which drugs you are taking, how much you have, and how often. It will grow back again.

*"At the time I had long blonde hair. When I understood I would lose it, I cut it short and got used to my new face. It wasn't easy, but friends and relatives encouraged me."*

Try a short hairstyle before it starts to fall out. You will have got used to having less hair. Also your friends and family will be used to you with short hair.

Use a soft hair brush and gentle shampoo.

When your hair starts to fall out, cut the remaining hair short. It usually looks better.

Avoid hairdryers and heated rollers. Don't have your hair permed or coloured – it weakens the hair.

Don't shave your head as small cuts may become infected.

If you want a wig, try to get a hairdresser to visit you before your hair starts to fall out. It will be easier to match your colour and style, if that is what you want.

Some girls prefer to wear a soft scarf or turban. Some girls prefer not to cover their head at all. Some men choose a wig, others wear a baseball cap or hat, others prefer to be bare-headed.

In Winter, put on a hat when you go outside. In Summer, put on a high factor sunscreen and wear a sunhat.



## Infection

### *Why does chemotherapy make me more likely to catch infections?*

The drugs kill other cells not just lymphocytes. The other cells, particularly neutrophils, protect you from infection.

### *When am I most likely to get ill?*

About 7-10 days after a chemotherapy treatment. The neutrophil count starts to drop after a treatment, and is at its lowest about 10 days later. From then on the bone marrow recovers and starts making neutrophils again.

### *How can I avoid infection?*

Follow any advice you are given by the hospital. Read the section on good hygiene below. If you are feverish or unwell, contact your GP or hospital the same day. See section on Temperature, page 20.



## Good body hygiene

Have a bath or shower every day. Wash and dry extra well in hot sweaty parts, like under your arms and between your legs. This will help control the bacteria on the surface of your skin.

Wipe your bottom from front to back after opening your bowels. Wash your bottom carefully after going to the toilet if you have diarrhoea. See section on Diarrhoea, page 23.

Wash your hands well after going to the toilet.

Chemotherapy can disrupt your periods, see Fertility and Sex, page 25. Use pads rather than tampons if your period comes when your white cell count is low.

Wash your hands very well before eating food.

Don't shave if you are neutropaenic. Skin can get drier than usual. Use unscented, mild or neutral soaps and shampoos. Light bath oil such as E45 can keep skin smooth and supple.

Try to avoid cuts and grazes. If you do have any, check that they are not getting infected, sore and inflamed.

If you already have pierced ears, take extra care to keep the holes clean. If you want to pierce your ears, don't do it now. Wait until you are sure that your treatment has ended.

Cut finger and toenails with extra care. Don't make them too short, you may cause damage and infection.

## Mouth care

Just like lymphoma cells and hair cells, the cells in your mouth divide rapidly. So your chemotherapy will affect them as well. Your mouth may develop ulcers and sores.

You are at most risk 7-10 days after a chemotherapy treatment, and from then on until your white cell count is back to normal.

*"They gave me lots of mouthwashes. Use them - otherwise you'll be sorry. I didn't bother to start with and my mouth got really sore."*

A tiny sore that you wouldn't usually worry about can lead to serious infection.

If you can feel a sore or mouth ulcer, tell a doctor or nurse straight away. It can be treated quickly and then won't get too bad.

Clean your teeth and mouth very gently after every meal and before you go to bed.

Use a small-headed soft nylon toothbrush.

Go to your dentist for a check-up. Tell them you are having chemotherapy treatment for lymphoma.

If you wear a brace you should discuss this with your doctor and dentist before treatment. You may be advised to stop for a while.

If you keep wearing a brace, clean it after all meals and snacks.

Lip salve or Vaseline can help prevent cracked lips.

If your mouth is sore, drink plenty of water.

Spicy and salty foods will make your mouth worse.  
Forget salt and vinegar crisps or chilli tortilla chips for a bit!

## Taste changes

Food may taste peculiar when you are on chemotherapy. Don't worry, your taste should return to normal.

Lots of people find ginger cake and ginger beer still keep their taste.

# Temperature



No matter how careful you are, you may get an infection. Tell someone if you feel ill. Take your temperature.

A raised temperature is a sign of infection.

Normal body temperature is **37 degrees centigrade** (°C).

If you feel unwell, or hot, or flushed, take your temperature, using a centigrade thermometer.

If your temperature is between **38** and **38.5** take it again in half an hour.

If it is still raised, phone the hospital straight away.

If you don't have a temperature but still feel unwell tell your doctor.



Don't bring down your temperature with paracetamol in any form. Wait until a doctor who knows you have lymphoma tells you to. NEVER take aspirin or anything with it in. It affects blood clotting; when your platelet count is low aspirin can cause serious internal bleeding.

# Digestion Problems

## Nausea and vomiting

Nausea is feeling sick.

Vomiting is being sick.

### *Will I be sick?*

Chemotherapy can make people feel and be sick. This doesn't happen to everyone.

*"They told me I would be sick, but I wasn't - I felt fine most of the time."*

### *Will I feel sick all the time?*

Nausea doesn't usually last more than 12-24 hours if you get it at all.

### *Can anything be done?*

Yes. There are very good anti-sickness pills or injections you can have. Remember to tell your doctor or nurse if you felt sick last time.

### *What can I do to help?*

Try some of the hints other young people have given. Some may work for you.

Keep drinking even if you feel sick. If you don't you may feel even worse.

Suck ice-cubes. Drink fizzy water.

Eat small amounts often.

Eat slowly. Don't watch other people eating.

Keep away from the smell of food being cooked.

Wear travel sickness wristbands.

Distract yourself with music, TV, games, cards etc.

Listen to relaxation tapes - there will probably be some on the ward.

If you get a strange taste in your mouth when a drug is being given, try sucking a mint, or a lemon sweet.

## Constipation

### *Why am I constipated?*

There are a number of possible reasons. Some chemotherapy drugs can cause it. Certain pain-killers can also make it difficult to go. You may be eating and drinking less than usual. You are probably less active than usual.



### *What can I do about it?*

Make sure you drink at least 2 litres a day. Tell your nurse or doctor.

Eat more high-fibre foods. Bran flakes, fresh fruit, fresh vegetables, baked beans etc.

Try to spend as much time as possible out of bed and moving around.

Warm drinks can help.

*"I was told about lots of side effects of chemotherapy - thank God I didn't get them all, but it seems to take ages for my bowels to settle down."*

# Diarrhoea

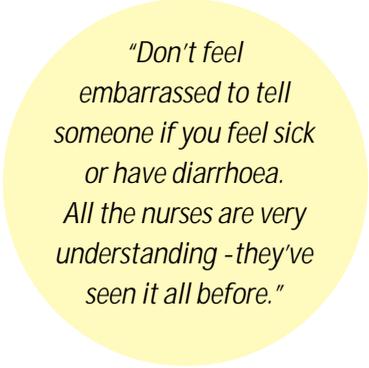
## *Why have I got diarrhoea?*

There are two main possibilities.

The cells that line the intestines divide rapidly and therefore are affected by chemotherapy. This can lead to diarrhoea.

OR

You have got an infection because your neutrophil count is low.



*“Don’t feel embarrassed to tell someone if you feel sick or have diarrhoea. All the nurses are very understanding - they’ve seen it all before.”*

## *So, what can I do?*

Tell a nurse or doctor. If the diarrhoea is caused by infection you can have antibiotics.

Make sure you have plenty to drink.

Cut down on fresh fruit for a bit.

Eat small meals often.

Avoid fried food.

A warm bath can help if you have a sore bottom.

Wash your hands extra carefully.

# Eating Well

Eating well will mean you can develop strong, new and healthy cells.

Some foods you used to like may not taste so good any more.

If one of your drugs is a steroid, you may gain weight and have a good appetite.

Your diet will need to be well-balanced with plenty of protein, starch, vitamins, minerals and fibre.

Avoid foods such as soft cheese, paté and live yoghurt when your blood count is low.

If you feel hungry, eat. Don't feel you have to wait for mealtime.

On the days you have a good appetite, eat extra.

When you're in hospital, ask friends and family to bring in your favourite foods.

Try to eat with other people.

Hot chocolate or cold milk shakes are good when you don't feel like solid food.



# Fertility and Sex

## Fertility is the ability to have a child.

During treatment for cancer it is common for both men and women to become temporarily infertile.

If you are having radiotherapy to the lower abdomen, special care will be taken to protect your sexual organs.

Some chemotherapy drugs affect fertility more than others.

If you are a man, and your treatment is likely to cause permanent infertility, you should be offered sperm banking. Your sperm is frozen, and may be used at a later date to try to make a partner pregnant. This has a reasonable chance of success.

If sperm banking has not been discussed, make sure you ask before treatment starts.

If you are a woman, at present there are no facilities for banking ova (eggs). However, medical advances can come in quickly. Make sure you ask to be certain of the current situation.

A lot of people treated for lymphoma go on to have normal healthy children. They are just as cheeky as everyone else's!

*"All the treatment I had for Hodgkin's disease did not affect my being able to get pregnant. Louise is 3 months old now, and she is very special."*



## Sex

If you have started having sex please read this section carefully. Because cancer treatment affects rapidly dividing cells, great care should be taken to avoid pregnancy at this time.

You cannot assume you are infertile during treatment. You should use a reliable contraceptive.



If you think you are pregnant, or you have made anyone pregnant whilst on treatment, you should talk to a nurse or doctor straight away.

If you are a woman and take the contraceptive pill, you may need to stop taking it. If no-one has talked to you about this and you are on the pill, please ask.

People with lymphoma often have low energy levels. This can also apply to their sex drive. Some men may be temporarily impotent.

Some girls may not feel sexually aroused.

Try not to worry; sex should return to normal once you are over your treatment.



# Hospital

It is possible that you will have to spend some time in hospital during treatment for lymphoma.

How much time you actually have to stay in hospital will vary.

*"I've got my own room at home, so being in a ward with other people around all the time was weird. After a bit I realised I could just draw the curtains round my bed when I wanted to be alone."*

## *Is there a ward for people my age with cancer?*

This all depends on where you live and what is available at the time. Some regions have special units for adolescents. In other areas you may be treated in a ward for adults, or children.

## *Do I get a choice?*

If you go to hospital as an emergency there may not be time to consult you. Otherwise you will probably be given a choice. If you are not, there may be a good reason. Please ask.

## *How do I choose?*

If there is a place on a young persons' unit, take it. They are designed with your needs in mind, and the staff will be experienced in working with young people with cancer. If not, probably the best way to choose is to ask to see the wards for yourself. Some young people find little children noisy and irritating, and would prefer an adult ward. Others find the adult wards boring and depressingly quiet. You and your family may need to weigh up the facilities available against the distance away from your home.

If you haven't stayed in hospital before, you may have some rather strange ideas about it. On television and in books people are almost always lying in bed. You will probably spend far more time up and about than you thought.

There is usually a day room where you can watch television or listen to music.

There may be a kitchen where you can make drinks, often with a fridge where you can keep your food.

There may also be a quiet or study room where you can read or do school or college work.



Bring things from home to make your space friendly and comforting.

Wear your own clothes, and get dressed whenever you can.

Whenever possible ask friends as well as family to visit you.

Keeping in touch with what's going on at school, college or work, can help you feel more 'normal'.

## People

You will see a lot of different staff; it can be a bit confusing trying to work out who's who. The guide below should help.



## Doctors

In overall charge of your treatment will be a senior doctor or consultant. You won't necessarily see them every day when you are in hospital, or at every outpatient visit. You can ask to see them specifically if you have particular worries. You can also make a separate appointment. Your consultant's secretary can often help.

Your consultant will either be a **haematologist** – a doctor who specialises in blood disorders. Or he or she may be an **oncologist** – a doctor who specialises in cancers.

You will have a team of doctors who you will probably see more often – registrars, senior house officers and house officers.

If you are having radiotherapy you will see a **clinical oncologist** – an oncologist who specialises in using radiation to treat disease.

## Nursing staff

Many hospitals now use a system called 'team nursing'. This means that you will be introduced to a particular nurse who will be responsible for looking after you with other nurses on his or her team. Your nurse is the person to talk to about anything that is worrying or upsetting you. It doesn't have to be about lymphoma, it could be about someone or something in the ward.

There may be a **Macmillan nurse** who can help you and your family understand about cancer. They can arrange a lot of help, especially at home.

## Other people

A **radiographer** takes X-rays, and may give radiotherapy. They are not doctors but have studied a lot about X-rays. They may also do scans.

There may be a hospital **social worker**. You could talk to them about money problems, or coping when you go home.

There may be a hospital **teacher** who can help with school or college study.

## Asking questions

This can sometimes be a problem. If you were older, you might feel more confident about talking to medical staff. If you were younger, you'd probably just ask questions as they came into your head.

You may feel embarrassed, or worry that people might think you are stupid if you forget something, or don't understand. But getting answers to your questions can be very important and can save you a lot of time and energy worrying.

It is also worth remembering that people are very different. Some young people like to know everything about their illness and its treatments. Others are happy just to know what it's called and that something is being done to try to cure them.

The doctors and nurses won't know which sort of person you are, unless you tell them. They may think that, if you don't ask questions, you are happy with things as they are.

So the message is, if there is something you want to know, ask. If you don't understand, or forget the answer, ask again.



## Waiting

It is likely that you will get bored at times in hospital. It is certain there will be times when you have to wait. Most people find the best way to cope with waiting, boredom and anxiety is having something to distract them. You could try some of their hints.

*"It's hard to make waiting easier. You just have to do your best and try to remember that no-one is doing it to you on purpose."*

If you are still at school or college, you could try to do some work or reading when you feel well enough. It is a good distraction, and means you will have less to catch up when you are well again.

Take a favourite magazine.

Get into an easy book like an adventure, romance, or detective story.

Do a crossword – ask people nearby if you get stuck on a clue, you might make a friend.

Listen to tapes or radio on a personal stereo.

Play a computer game - with the sound off or you'll drive other people crazy.

Have a pack of playing cards – patience cards are good because they are small.

Write down any questions - there's nothing worse than waiting ages, seeing the doctor, and then realising afterwards that you forgot to ask something. Write the answers down too.

Try chatting to other people waiting.

Do some deliberate day-dreaming.  
For example imagine your ideal holiday.

Start a diary and update it when you have to wait.

# Going Home

Just as hospital can seem weird and like another world, so can the thought of going home.

Even if you haven't been in hospital very long, you will have got used to the people and the surroundings. You may have been counting the days, hours and minutes till you can leave, and then feel scared when it actually comes to it.

Try not to worry; just as you got used to being in hospital, you will get used to being at home again.

## Parents

*Why are my parents trying to run my whole life? They weren't like this before.*

It is common for parents to be more protective and controlling than before. It may help to remember that this is because they are worried, and they care about you. When you are home they feel extra responsibility for making sure you continue to get better.

Try talking to them when you are not feeling angry. Say what you don't like, and try to agree some rules together.

*My mum is driving me mad, she keeps doing everything for me. What can I say to stop her?*

In a quiet moment you could try to work out a deal. Something like, "I agree to ask for help if I need it. You agree to let me do things by myself."



## *My parents used to let me go out with friends, now they're trying to stop me.*

Again pick a moment when all of you are calm. You could try the same approach. For example, "You agree to let me go out with friends as normal. I agree to stay in if I feel tired or unwell."

Remember that if you are neutropaenic you should avoid clubs, cinemas and other crowded places like steamy buses and tube trains.

You may find it helps to ask someone outside the family to talk to you all. Perhaps a district nurse or a family friend could listen to both sides and help you to work something out.

If you had moved into your own place, but are now back with your family, things can seem especially tough. Just when you had got your own space and independence you have had to give it up. Bear in mind this can work both ways, your family may be finding it hard to re-adjust to you as well.

## Brothers and sisters

Your illness may affect how you get on with your brothers and sisters. You may find they are irritating if you are having an off day, and may snap at them. Perhaps next day when you are feeling better you could say you're sorry and explain that sometimes you feel ill and that makes you cross.

They may be jealous, seeing only the extra attention you have been getting. Perhaps you will feel jealous of them. They may be playing sport or going out to a club, when you're still finding it an effort to climb stairs.

Try explaining feelings to brothers and sisters – they may surprise you with their support.

*"Some of my friends let me down. They stopped coming round. But my sister was great - she brought her friends home and we talked and played CDs. It made all the difference."*

# Friends

Your friends will probably know nothing about lymphoma and its treatment. They will not know how you feel or what has happened to you. How much you tell them about the disease itself is your choice.

You may look different; you may have lost or gained weight. If you have had chemotherapy your hair may be different, or still be re-growing.

You will be used to how you look, but don't be surprised if friends or work-mates are awkward or embarrassed. Often you will need to make the first move and explain things. If you talk to them first and answer their questions, they will realise that you are still you!

After a while your treatment will probably fall into a pattern. You will have a good idea of which days are likely to be good and bad. Plan to do things with friends on the 'good days'

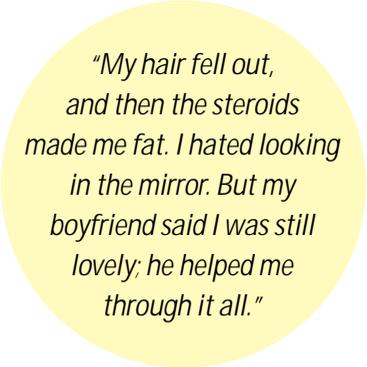
If there is some event you would really like to go to with friends, you could ask the hospital if your treatment can be scheduled round it.



## Partners

If you have a partner this will be a testing time for you both. You have been very unlucky. Usually young people do not have to think about, let alone cope with, serious illness.

Perhaps you and your partner will stay together throughout. Maybe one of you will find it all too much.



*"My hair fell out, and then the steroids made me fat. I hated looking in the mirror. But my boyfriend said I was still lovely; he helped me through it all."*

## School, college, work

Both lymphoma itself and your treatment, can leave you feeling very tired.

Although you may very much want to keep up with your studies you could find yourself low on energy for some while.

You may want to arrange to see a particular teacher or tutor on a regular basis to talk about your progress.

Repeating a course of study may be better than pushing too hard and getting tired.

If you are at work it is probably easiest to tell the personnel officer or your boss about your illness. Whatever type of lymphoma you have, you will certainly need some time off work.

Everyone reacts differently to treatment. Some people are able to work on their good days, others need a longer time off work.

If you have worries about work, talk things over with your doctor, or with the hospital social worker.

# Treatment Options and Trials

## *Do I have a choice about my treatment?*

If there are treatment options, these should be explained to you. It is a doctor's duty to recommend what they believe to be the best treatment for you. If there is one treatment which your doctor considers the best, you would not be offered a choice. No treatment can be carried out without your agreement.

## **Certain treatments are given only after written agreement**

If you are under 16 the written agreement of your parent or guardian may be needed. If you are 16 or over you can sign on your own behalf. This written agreement to treatment is known as a **consent form**.

Neither you nor your parents may need to sign a consent form at all.

## *I have been told I can take part in a clinical trial. What does this mean?*

A **clinical trial** tests a new treatment against the best existing treatment or existing treatments against each other. A new treatment may involve using new drugs, or it may use the same drugs, but in different amounts or at different times.

Clinical trials are designed to test alternative treatments as safely as possible. If people did not take part in them, it would be difficult for improvements to be made. A lot of progress has been made as a result of national clinical trials.

Clinical trials are often **randomised**. This means that the treatment you receive is allocated by chance, not by you or your doctor.

A committee of experts and advisers has to believe that any new treatment is as good as the existing one, and that there is evidence that the new treatment may be better.

Trial results are checked at regular intervals. If one treatment is clearly better, then the trial is stopped and that treatment is given to everybody.

If you decide not to take part in a trial, you will be given the best existing treatment.

