

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", 7th.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.

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

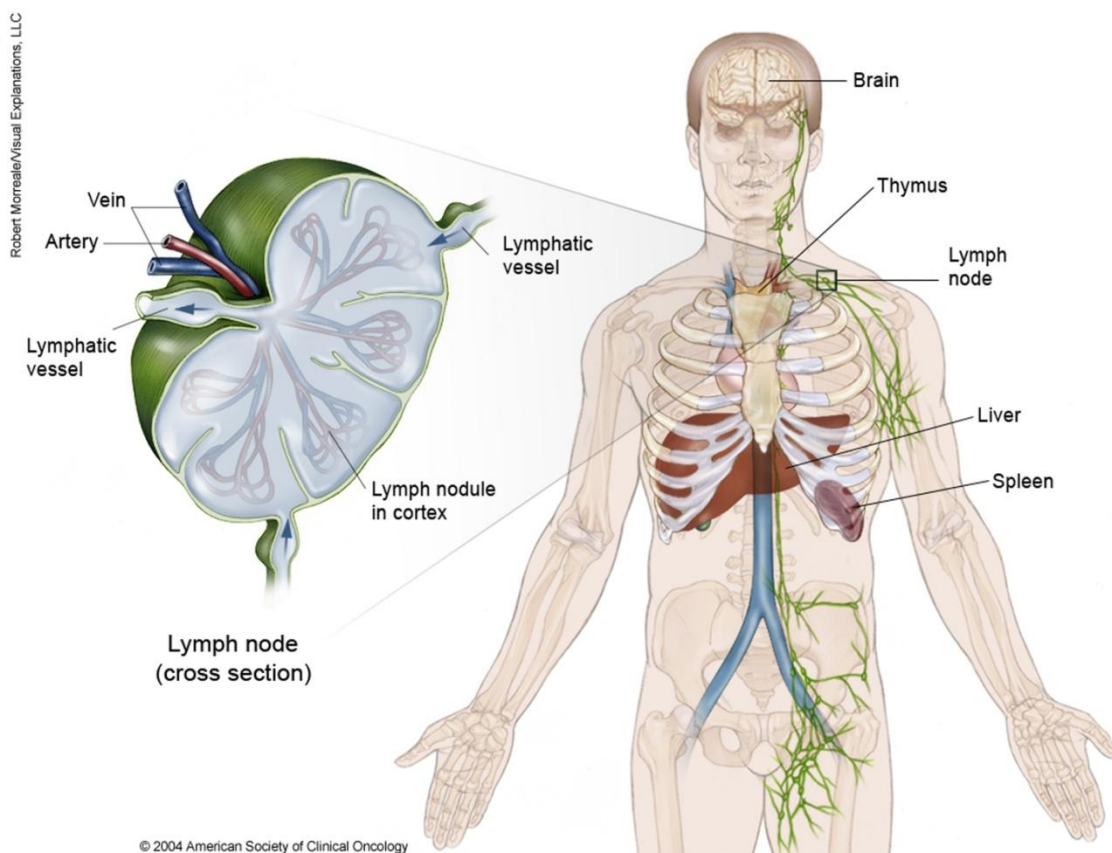
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Hodgkin lymphoma

This booklet is for you if you have or someone close to you has Hodgkin lymphoma..

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you.



Anatomy of a Lymph node and the Lymphatic system

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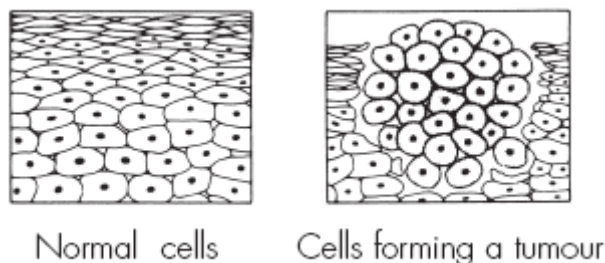
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What is lymphoma?

Hodgkin 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, this division of cells takes place in an orderly and controlled manner. However, if for some reason the process gets out of control, the cells continue to divide. Then there may be too many immature white blood cells in the blood or bone marrow. A lump or tumour may then develop in one or more groups of lymph nodes.



Lymphoma cells generally start to grow in lymph nodes (also called lymph glands). Usually, Hodgkin lymphoma 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.

Lymphoma cells 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.

As there are lymph nodes and lymph vessels throughout the body, Hodgkin lymphoma can start in any part of the body. The most common place for it to start is in the lymph nodes in the neck. The next most common places are the lymph glands:

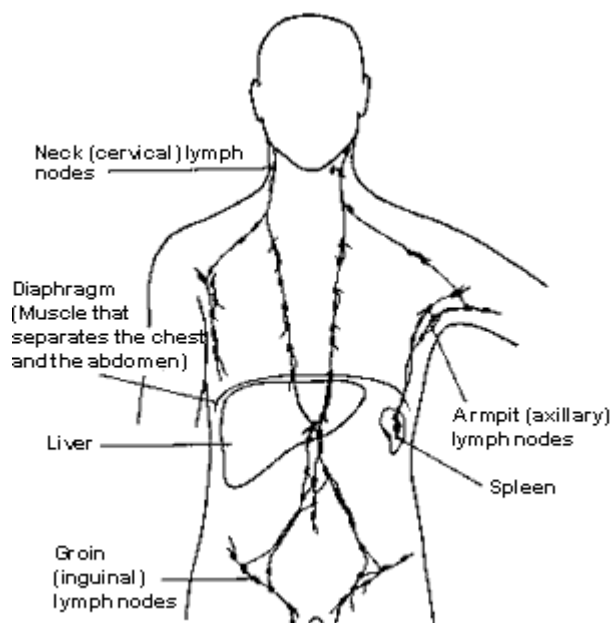
- under the arms (axilla)
- in the chest
- in the groin
- in the abdomen.

Hodgkin lymphoma can also occur in body organs. In some people it can affect the liver, lungs or bone.

The treatment of Hodgkin lymphoma is usually very successful, even when it has spread to different areas of the body. Most people can now be cured, or the lymphoma can be controlled for many years.

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 thymus, the spleen, and lymph nodes. They are connected by a network of tiny lymphatic vessels. Lymph nodes are found mainly in the neck, armpit and groin. Their number varies from one part of the body to another. In some parts of the body there are very few, whereas, for example, under your arm there may be between 20 and 50 nodes (see diagram below).



The position of lymph nodes in the body

Circulating through the lymphatic vessels is milky-looking fluid called lymph, which contains lymphocytes. Lymphocytes are white blood cells. They 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 larger. 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 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 Hodgkin lymphoma?

Hodgkin lymphoma is a cancer of the lymphatic system. It is sometimes called Hodgkin disease.

There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). Most lymphomas are non-Hodgkin lymphoma and only about 1 in 5 (20%) are Hodgkin lymphoma. Nearly 1500 people are diagnosed with Hodgkin lymphoma in the UK each year.

The difference between Hodgkin lymphoma and NHL

There is only one way to tell the difference between Hodgkin and non-Hodgkin lymphomas (NHL). The difference can be seen when the cells are looked at under the microscope. Often the cells need to be stained with dyes to show their structures. Usually the cells will also be tested for the presence of particular proteins – this is known as immunohistochemistry.

In most cases of Hodgkin lymphoma, a particular cell known as the Reed-Sternberg cell is found in the tests done to see if you have the disease. This cell is not usually found in other lymphomas, so they are called non-Hodgkin lymphoma. This difference is important, because the treatment for Hodgkin and non-Hodgkin lymphomas can be very different. It is thought that Reed-Sternberg cells are a type of white blood cell – a B-lymphocyte that has become cancerous. B-lymphocytes normally make antibodies to fight infections.

JASCAP has a separate booklet about non-Hodgkin lymphoma.

Causes of Hodgkin lymphoma

Although the cause of Hodgkin lymphoma is unknown, research is going on all the time to find the cause. Hodgkin lymphoma is more common in younger people in their 20s, although it can occur at any age.

Some factors can contribute to the development of Hodgkin lymphoma. These include:

- poor immunity: for example, in people who are taking medicines after an organ transplant; in people who have HIV, and some rare medical conditions that reduce immunity
- infection with the Epstein Barr virus (which causes glandular fever) may slightly increase the risk of developing Hodgkin lymphoma later in life.

Hodgkin lymphoma is not infectious and cannot be passed on to other people. Other members of your family will not be more likely to develop Hodgkin lymphoma, just because you have it, unless you have an identical twin. The identical twin of someone with Hodgkin lymphoma has a very slightly increased risk of developing it themselves.

Symptoms of Hodgkin lymphoma

The first symptom of Hodgkin lymphoma is usually a swelling of lymph nodes in the neck, armpit or groin. The swellings are usually painless, but some people may find that they ache.

Other symptoms may include any of the following:

- drenching and/or frequent sweats – especially at night
- unexplained high temperatures
- weight loss
- tiredness
- a cough or breathlessness
- a persistent itch all over the body.

The commonest of these symptoms are high temperatures, sweating, and weight loss. These are known as 'B symptoms'.

Other symptoms will depend on where in the body the enlarged lymph glands are.

A small proportion of people with Hodgkin lymphoma have abnormal cells in their bone marrow when they are diagnosed. This can lower the number of healthy blood cells in the blood. Low numbers of healthy blood cells can cause the following symptoms:

- breathlessness and tiredness
- an increased risk of infections
- excessive bleeding: such as nose bleeds, very heavy periods in women, or tiny spots of blood under the skin.

Very rarely, people with Hodgkin lymphoma may have pain in the affected lymph gland when drinking alcohol.

If you, or your child, have any of the above symptoms, it is important to have them checked by your GP. But remember, they are common to many conditions other than Hodgkin lymphoma. Most people with these symptoms will not have Hodgkin lymphoma.

How Hodgkin lymphoma is diagnosed

Usually you begin by seeing your GP (family doctor) who will examine you and arrange for you to have any further tests or x-rays that may be necessary. 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. A blood test and chest x-ray may be taken 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 is a small operation, usually done under general anaesthetic.

Further tests for Hodgkin lymphoma

If the biopsy shows that Hodgkin lymphoma is present, your specialist will want you to have some further tests to see if the lymphoma has spread to other parts of the body. This shows the stage of the lymphoma.

Once your doctor knows where the Hodgkin lymphoma is in your body, and whether or not you have symptoms, they can plan the most effective treatment for you.

The tests to find out the stage may include any of the following:

- Blood tests
- Bone marrow sample
- Chest x-ray
- CT scan (computerised tomography scan)
- MRI scan (magnetic resonance imaging scan)
- PET (positron emission tomography) scan

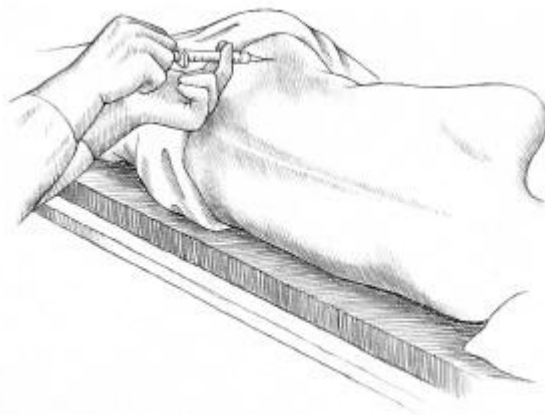
Blood tests

Blood samples will be taken throughout your treatment to check your general health, the levels of red and white cells and platelets in your blood, and your liver and kidney functions.

Bone marrow sample

A sample of bone marrow is taken, usually from the pelvis, and examined to see if it contains any lymphoma cells. The test doesn't take very long and can be done on the ward or in the outpatient department. If you are very anxious about the test a mild sedative may be helpful. You can ask your doctor about this beforehand.

Before the sample is taken, a local anaesthetic is used to numb the area. A needle is passed through the skin into the bone marrow. A tiny piece of the bone and bone marrow are taken into the syringe to be examined under the microscope. A small dressing is applied to the area after the procedure. The test can be painful and you will need to take painkillers afterwards. The discomfort may last for a few days, and painkillers may be necessary during this time.



A sample of bone marrow biopsy being taken

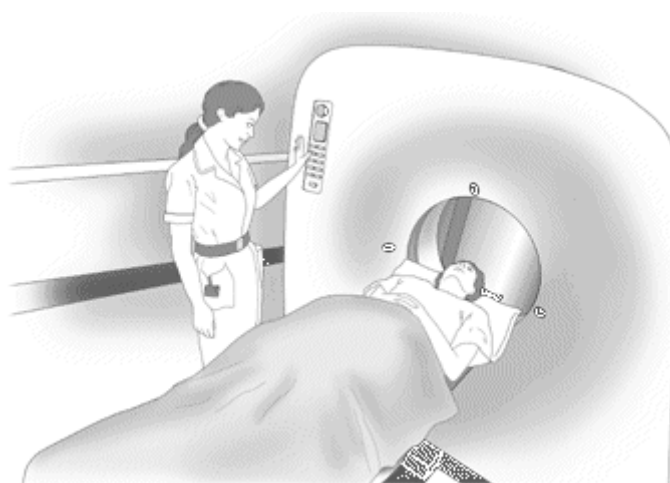
Chest x-ray

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

CT scan (computerised tomography scan)

A CT scan takes a series of x-rays which builds up a three-dimensional picture of the inside of the body. The scan is painless but takes from 10—30 minutes. CT scans use a small amount of radiation. The radiation is 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 once the scan is over.



CT Scan Machine

MRI scan (magnetic resonance imaging scan)

This test is similar to a CT scan but uses magnetism instead of x-rays to build up a detailed picture of areas of your body.

During the test you will be asked to lie very still on a couch inside a long tube for about 30 minutes. The scan is painless, but can be slightly uncomfortable. Some people feel a bit claustrophobic during the scan. It is also noisy, but you will be given ear plugs or headphones to wear. You may be able to take someone into the room with you to keep you company.

Some people are given an injection of dye into a vein in the arm, but this is not usually uncomfortable.



A MRI Machine

PET (positron emission tomography) scan

PET scans are a new type of scan and you may have to travel to a specialist centre to have one. They are not always needed 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 beyond the original area of the body. They may also be used 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 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 the arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

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 before you go home. Obviously this waiting period is an anxious time and it may help you to talk things over with a close relative or friend.

Stages of Hodgkin lymphoma

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original area. Knowing the extent of the cancer and the type (see opposite) helps the doctors to decide on the most appropriate treatment. The most commonly used staging system for Hodgkin lymphoma is outlined below:

Stage 1 One group of lymph nodes is affected

Stage 2 Two or more groups of lymph nodes are affected on the same side of the diaphragm (the sheet of muscle underneath the lungs)

Stage 3 Lymph nodes above and below the diaphragm are affected

Stage 4 The lymphoma has spread outside the lymph glands to organs such as the liver, bones or lungs.

If the Hodgkin lymphoma comes back after initial treatment, this is known as **recurrent lymphoma**.

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 a

significant amount of weight or have fever or night sweats. If you have none of these symptoms your lymphoma will be classified as A. If you have one or more of them it is classified as B.

Types of Hodgkin lymphoma

There are different types of Hodgkin lymphoma. In each type, the cells have a particular appearance when they are looked at under a microscope. They also have different types of protein on their surface which can be detected by immunohistochemistry. The standard way of grouping Hodgkin lymphomas is the World Health Organisation (WHO) lymphoma classification system.

The WHO system divides Hodgkin lymphoma into two main groups: **classical types** and **nodular lymphocyte-predominant type**.

Classical types of Hodgkin lymphoma are further divided into four groups:

- nodular sclerosis
- mixed cellularity
- lymphocyte-depleted
- lymphocyte-rich.

Treatment for Hodgkin lymphoma

- Types of treatment
- How treatment is planned
- Giving your consent
- Benefits and disadvantages of treatment
- Treatment decisions
- Second opinion

Types of treatment

The main types of treatment for Hodgkin lymphoma are chemotherapy and radiotherapy. You may need to have either of these, or a combination of both.

Many people with Hodgkin lymphoma can be cured, even when the lymphoma has spread to different areas of the body.

Your doctor will plan your treatment based on the results of the staging tests (see page 16). Other factors will also be taken into account when planning your treatment, These include:

- your age
- your general health (including any other medical conditions)
- the specific type of Hodgkin lymphoma you have
- which parts of your body are affected
- the size of affected lymph nodes and whether the lymphoma is involving other organs
- whether or not you have symptoms such as high temperatures, night sweats or weight loss.

Your doctor will explain your treatment to you and the reasons why a particular treatment has been chosen.

Radiotherapy is sometimes used on its own to treat early-stage lymphoma. Early stage means that only one or two groups of lymph nodes are affected. However, chemotherapy is now often given instead of radiotherapy in early-stage lymphoma. When Hodgkin lymphoma is more widespread, chemotherapy is nearly always the main treatment.

If Hodgkin lymphoma does not respond well to standard chemotherapy, or comes back after standard treatment, high-dose chemotherapy with stem cell support may be used.

Treatments for Hodgkin lymphoma may occasionally cause serious long-term side effects. Some chemotherapy drugs can cause permanent infertility. However, this is less likely with some newer treatments. Treatment with chemotherapy and radiotherapy can lead to a slightly increased risk of developing another cancer later in life. However, modern treatments and approaches to treating Hodgkin lymphoma are designed to limit these risks as much as possible.

How treatment is planned

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

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

The team will often also include a number of other healthcare professionals, such as a:

- nurse specialist
- pathologist (a doctor who specialises in how disease affects the body)
- dietitian
- physiotherapist
- occupational therapist
- psychologist or counsellor.

Together they 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 is the right treatment 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. No medical treatment can be given without your consent, and before you are asked to sign the 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 possible other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not 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 often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask 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 important 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 frightened at the idea of having cancer treatments, because of the side effects that can occur. Some people ask what would happen if they did not have any treatment.

Although the treatments can cause side effects, these can usually be well-controlled with medicines.

Treatment can be given for different reasons, and the potential benefits will vary depending upon the individual situation. Many people with Hodgkin lymphoma will be cured with treatment. However, sometimes, if the lymphoma has come back after initial treatment, any further 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 without any of the benefits.

Treatment decisions

If you have been offered treatment that aims to cure your lymphoma, deciding whether to accept the treatment may not be difficult. However, if a cure is not possible and the treatment is to control the lymphoma 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 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 do 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 during the discussion.

Chemotherapy for Hodgkin lymphoma

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy the lymphoma cells by disrupting their growth. The drugs can reach lymphoma cells anywhere in the body through the bloodstream.

Our booklet on chemotherapy discusses the treatment and its side effects in more detail. Information about individual chemotherapy drugs, and combination chemotherapies and their particular side effects, is also available.

- How it is given
- Central lines
- Side effects
- Contraception
- Children and chemotherapy

How it is given

The drugs may be given as tablets or capsules, or by injection into a vein (intravenously) in your arm. A combination of several drugs is normally given over a few days followed by a gap of a few weeks. This is known as a 'cycle' of treatment. It allows your body and blood cells to recover from any side effects before the next treatment. Your treatment will probably last for several months. During this time you will have regular check-ups.

The treatment is usually given as an outpatient but sometimes it may mean spending a few days in hospital. The combinations of drugs most commonly used for Hodgkin lymphoma include:

ABVD involves the drugs doxorubicin (which is also known as Adriamycin), bleomycin, vinblastine and dacarbazine.

ChIVPP is a combination of chlorambucil, vinblastine, procarbazine and prednisone.

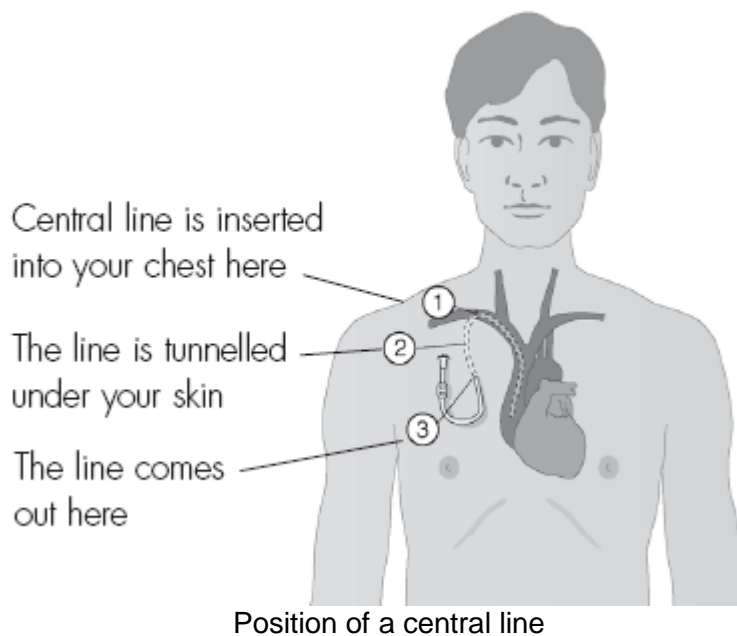
BEACOPP involves the drugs bleomycin, etoposide, doxorubicin (Adriamycin), cyclophosphamide, vincristine (Oncovin®), procarbazine and prednisolone.

Other drugs, or combinations of drugs, may also be used.

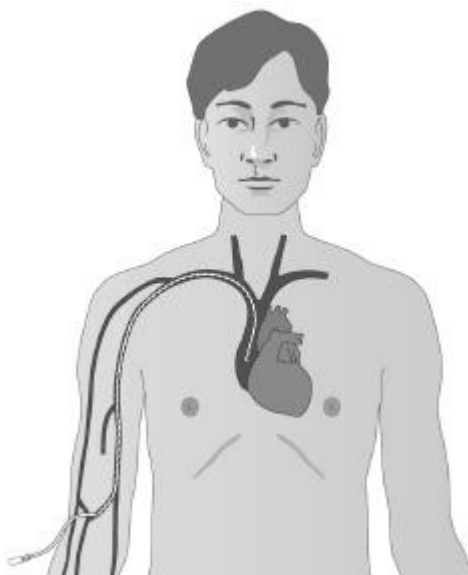
Central lines

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

Chemotherapy and other drugs can be given through the tube and blood samples can be collected. This saves you the pain or discomfort of repeated injections. The central line stays in place throughout your treatment. Once your treatment is finished, the line is taken out. A local anaesthetic maybe used if necessary.

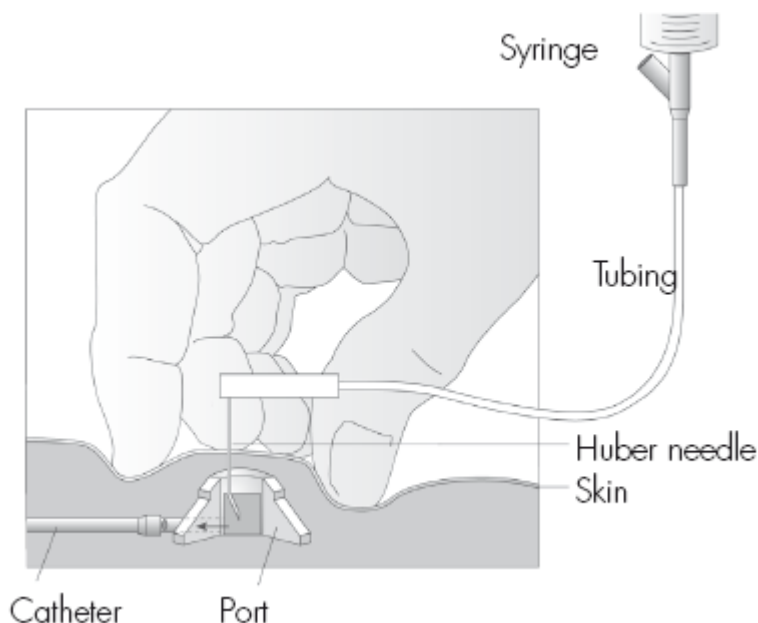


A PICC line (peripherally inserted central catheter) is like a central line, but is put into a vein in the bend of your arm, instead of your chest. You can have a PICC line put in as an outpatient, using local anaesthetic. Your PICC line can also stay in place throughout your treatment and can be used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



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

Some tubes end in small 'ports' that lie just under the skin of the chest: these are known as implantable ports. 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.



The implantable port is inserted just under the skin of the chest

Side effects

Chemotherapy can cause unpleasant side effects, but these can often be well controlled with medicines. The main side effects are described here, along with some ways of avoiding or reducing them.

Lowered resistance to infections

While the drugs are acting on the cancer 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 of growth factors may also be given to stimulate the production of white blood cells by the bone marrow.

If your temperature goes above 38°C (100.5°F), or you suddenly feel unwell even with a normal temperature, contact your doctor at the hospital straight away.

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. A drug called erythropoietin (EPO) may also be used to help your bone marrow produce more red blood cells.

Bruising and bleeding

Platelets are a type of blood cell which help to clot the blood. If the number of platelets in your blood is low you may bruise very easily or develop blood spots or rashes on the skin. You may suffer from nosebleeds or bleed more heavily from minor cuts or grazes. If you develop any unexplained bruising or bleeding, contact your doctor or the hospital immediately. We have a factsheet on platelet transfusions.

Feeling sick

Some of the drugs used to treat Hodgkin lymphoma may make you feel sick (nauseated) and possibly vomit. There are now very effective anti-sickness drugs (anti-emetics) to prevent or greatly reduce nausea and vomiting. Your doctor will prescribe these for you.

Sore mouth

Some chemotherapy drugs can make your mouth sore and cause small ulcers. Regular mouthwashes are important and your nurse will show you how to do these properly. If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet. The dietitian at the hospital can give you advice. You may find our booklet on eating problems helpful.

Hair loss

Unfortunately, some of the drugs used to treat Hodgkin lymphoma can make your hair fall out. Ask your doctor if the drugs you are taking are likely to cause hair loss or other specific side effects. People who lose their hair often cover this up by wearing wigs, hats, or scarves. Hospital in-patients can get a free wig from the NHS and your doctor or nurse will be able to arrange for a wig specialist to visit you. However, people being treated as outpatients usually have to pay for their wigs.

If your hair falls out due to chemotherapy, it will normally grow back over a period of 3–6 months after the treatment.

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

It is important to remember that chemotherapy affects different people in different ways. Some people find they are able to lead a fairly normal life during their treatment, but many find that they become very tired and have to take things much more slowly. Just do as much as you can and try not to overdo it.

Contraception

It is not advisable to become pregnant or father a child while having any of the chemotherapy drugs used to treat Hodgkin lymphoma, as there is a possibility that the chemotherapy drugs may harm the foetus. It is important to use effective contraception during your treatment and for a few months afterwards. You can discuss this with your doctor or specialist nurse.

Condoms should be used during sex within the first 48 hours after chemotherapy in order to protect your partner from any of the drug that may be present in semen or vaginal fluid.

Your doctor will tell you what problems, if any, to expect from your treatment.

Children and chemotherapy

Missing school

Many children worry a lot about missing school and falling behind with their work. It is important to reassure them that they will be able to catch up. Your child's doctor and the social worker at the hospital can help arrange a home tutor for your child during this time.

Social contact

Most children manage to go to school in between their cycles of chemotherapy. It is important to talk to the teachers about your child's illness and to ask them to let you know when there are any infections, such as chicken-pox or measles, in your child's class. It is also advisable not to let your child get over-tired, so games and PE are probably best avoided during the period of treatment.

Your child may be reluctant to go back to school, as they may feel embarrassed about hair loss. However, it is very helpful for your child to keep in touch with their friends. If this is a problem, discuss it with your doctor and with the schoolteachers.

Our booklet on children's cancers gives information and suggestions on coping with a child's illness.

Radiotherapy for 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.

Radiotherapy only treats the area of the body it is aimed at and so may be used when the lymphoma cells are contained in one or two areas of lymph nodes in the same part of the body (stages 1 or 2). It may be given in addition to chemotherapy.

The treatment is given in the hospital radiotherapy department, usually as daily sessions from Monday to Friday, with a rest at the weekend. The length of your treatment will depend on the type and stage of the lymphoma, but is normally about four weeks.

Planning your treatment
Treatment sessions
Side effects

Planning your treatment

To make sure the radiotherapy is as effective as possible, it has to be carefully planned.

On your first visit to the radiotherapy department you will be asked to lie under a large machine called a simulator, which takes x-rays of the area to be treated. Sometimes a CT scanner is used for the same purpose. Treatment planning is a very important part of radiotherapy and may take a few visits. The treatment is planned by a doctor: a clinical oncologist.

The radiographer, who gives you your treatment, will draw marks on your skin to help position you accurately and show where the rays are to be directed. These marks must stay visible throughout your treatment. However, they can be washed off once your treatment is over. Some people may have tiny, permanent marks (tattoos) made: these will only be done with your permission. At the beginning of your treatment you will be given instructions on how to look after your skin in the area being treated.

Treatment sessions

Before each session of radiotherapy the radiographer will position you carefully on the couch and make sure that 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 watch you from the next room. Radiotherapy is not painful but you have to lie still for a few minutes while your treatment is being given.



A radiographer watches on a monitor while treatment is given

Side effects

A course of radiotherapy will nearly always cause tiredness. Other side effects you have will depend on the part of your body being treated. Any treatment to the abdomen can cause stomach upsets such as feeling sick (nausea), vomiting or diarrhoea. Treatment to the head can cause hair loss. Radiotherapy to the neck can make your mouth, or throat, sore. You may also notice that some foods taste different from normal. These side effects can be mild or more troublesome, depending on the length of your treatment.

Your radiotherapist will be able to advise you what to expect. They 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. Your radiotherapist will be able to advise you what to expect. We also have information about coping with specific side effects, such as a dry mouth.

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 if you are concerned about long-term side effects.

Tiredness

As radiotherapy can make you tired, you should try to get as much rest as you can, especially if you have to travel a long way for treatment each day. Fatigue syndrome is a term often used to describe the tiredness that can occur during and after treatment. It generally begins in the latter half of treatment and can continue for several months or even years after treatment has finished. Balancing rest and activity throughout the day is important as your body needs rest to recover from the treatment.

Feeling sick (nausea)

Nausea can usually be effectively treated by anti-emetics (anti-sickness drugs), which your doctor can prescribe. If you don't feel like eating, you can replace meals with nutritious high-calorie drinks which are available from most chemists. We have information on managing nausea and vomiting.

Hair loss

Although radiotherapy can cause hair loss, this only occurs in the area being treated. For example, if you have radiotherapy to the lymph nodes in your neck, you may lose the hair on the back of the neck. Radiotherapy to the nodes in the chest may make the hair on your chest fall out.

When you have finished the course of treatment, your hair will usually grow back. It normally takes between six and twelve months, depending on the dose of radiotherapy and the length of treatment.

All these side effects will disappear gradually once your course of treatment is over. Let your doctor know if they continue.

Radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment.

Our booklet on radiotherapy discusses this treatment in more detail.

High-dose treatment with stem cell support for Hodgkin lymphoma

Some patients need to have very high doses of chemotherapy (sometimes with radiotherapy). This is done to improve the chances of curing the Hodgkin lymphoma. High-dose chemotherapy may

be given if standard chemotherapy has not completely got rid of your Hodgkin lymphoma. It may also be used if the lymphoma comes back after you have had standard chemotherapy. Your doctor will discuss with you whether high-dose treatment is necessary, and possible, in your case.

If you need to have high-dose treatment, you will also need to have a stem cell transplant (commonly called a peripheral blood stem cell transplant). Stem cells are the basic blood cells from which other cells develop. They can be collected directly from the blood or from the bone marrow. The bone marrow is the substance in the inner part of the bone which produces blood cells. Because high doses of chemotherapy will destroy your bone marrow, stem cells are given back to 'rescue' you from the effects of the high-dose treatment.

Although this treatment is often called a transplant, it is better described as stem cell support. This is because it is your own cells that are being collected and then returned to you. In the past, bone marrow, which contains stem cells, was often used but it is now more usual to take stem cells from the blood.

How are your stem cells collected and returned?

After chemotherapy, injections of a growth factor are given. Growth factors are proteins that make stem cells multiply and spill over from the bone marrow into the blood. The growth factor is usually given daily as a small injection under the skin (subcutaneously). You, or a relative, can be taught to do this, or a district nurse can give it. If you prefer, the injection can be given daily at the hospital.

When the number of different cells in your blood is at the right level, the stem cells will be collected. This takes about 3–4 hours and involves a drip being put into a vein in each arm. Blood is taken through the drip into a machine called a cell separator, which spins it to separate out the stem cells. These are collected and the rest of the blood is given back to you through a vein in your other arm.

The stem cells are frozen until you have had the high-dose chemotherapy. Then they are thawed out and given back into your vein by drip.

Some people may have a transplant from another person (**allogeneic transplant**), rather than their own cells (**autologous transplant**).

Stem cell and bone marrow transplants are complicated treatments and carry some risk. Because of this they are generally carried out in specialist cancer treatment hospitals. This means you may have to be treated in a hospital some distance from your home.

Anyone with Hodgkin lymphoma who has had high-dose treatment should be given blood or platelet transfusions that have been irradiated. This lowers the risk of the donated blood cells from reacting against the patient's own blood cells. Patients who have had this treatment should carry a card or wear a Medicalert so that hospital staff are aware of this in case of an emergency.

We have a booklet on stem cell and bone marrow transplants which gives more information on this treatment.

Steroid therapy for Hodgkin lymphoma

Steroids are drugs which are often given with chemotherapy to help treat Hodgkin lymphoma. They also help you feel better and reduce nausea.

Side effects

Steroids for Hodgkin lymphoma are generally given only for a few months and so usually have few side effects. The effects that you may notice include:

- an increased appetite

feeling more energetic
difficulty in getting to sleep.

Whenever possible, it is better to take steroids early in the day, so that they do not disrupt your sleep too much.

It is unusual for people with Hodgkin lymphoma to have to take steroids for a long time, but if you do, you may have some other temporary side effects which can include:

puffiness of the eyelids, hands, fingers and feet
indigestion
raised blood pressure
weight gain
a slightly greater risk of getting infections.

You may also develop an increased level of sugar in the blood. If this happens, your doctor will prescribe drugs which will need to be taken 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. Your 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. You should carry a card with you stating that you are taking steroids. The pharmacy or staff at the hospital will give you the card when they give you your steroids.

Our booklet on steroids gives more information about these drugs and their possible side effects.

Follow-up after treatment for Hodgkin lymphoma

After your treatment has finished you will be asked to attend the hospital for regular check-ups. To begin with, these may be every three months or so and will include a physical examination, and occasional blood tests and chest x-rays.

Over time, the appointments will gradually become less frequent. If you are having any problems, or notice any new symptoms between these times, let your doctor know as soon as possible. Sometimes PET scans may be used to check whether all the lymphoma has gone after treatment.

Our booklet on adjusting to life after cancer gives useful advice on how to keep healthy and adjust to life after cancer.

If Hodgkin lymphoma comes back

For many people, treatment will completely cure their lymphoma. Other people, however, may find that their lymphoma comes back. If this happens, it may be possible to give more treatment with the aim of curing the disease. Usually this would be chemotherapy or radiotherapy, or a combination of both, or high-dose treatment. The treatment you are given if the lymphoma comes back will partly depend upon what treatment you had initially and where it has come back.

Even if it is not possible to cure the lymphoma, treatment can be given to shrink the lymph glands and control it to keep you well, often for long periods of time.

How treatment for Hodgkin lymphoma might affect your fertility

Many couples have had healthy babies after one of them has been treated for Hodgkin lymphoma.

Unfortunately, however, some treatments for Hodgkin lymphoma, and sometimes the lymphoma itself, can cause infertility. Your doctor or specialist nurse will talk to you about this before you start your treatment. If you have a partner, you may find it helpful to see the doctor together so that you can both discuss any fears or worries that you may have.

Some precautions can be taken to reduce the risk of infertility. If men have radiotherapy to the abdominal area, a lead shield may be able to protect the testes. In women it is sometimes possible to move the ovaries out of the treatment area by an operation before radiotherapy begins.

Some combinations of chemotherapy drugs do not cause infertility. With some drugs, however, the risk of either temporary or permanent infertility is high.

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 have so you can be sure you are clear about your treatment.

Men
Women
Coping with infertility

Men

Sometimes it is possible for men to store sperm before starting treatment. Parents of teenage boys should also be aware of this so that, if possible, sperm can be stored for use in later years.

Women

Most women find that their menstrual periods stop or become irregular during treatment. The periods may return to normal once the treatment is over, so it is very important to continue to use contraception during and after your treatment. The nearer a woman is to her natural menopause, the more likely it is that chemotherapy will stop her periods permanently. Women whose periods stop can be given hormone replacement therapy (HRT). This does not restore fertility, but it prevents the possible development of menopausal symptoms. Menopausal symptoms can include hot flushes, dry skin, low sex drive, and dryness of the vagina which can make sex uncomfortable.

It may be possible to store fertilised eggs (embryos), with the chance of re-implanting them later. This could be worth considering if you and your partner want a child, and you are going to have chemotherapy which is likely to affect your fertility. For this to be possible, the lymphoma needs to be at a stage where the treatment can be delayed for several weeks while the eggs are collected and fertilised. Research is going on into storing unfertilised eggs or ovarian tissue, which contains immature eggs, hoping at some time in the future to be able to help women conceive. However, this research is still at an early, experimental stage and is not widely available.

Coping with infertility

If chemotherapy has made you infertile, it can be very difficult to come to terms with the fact that you can no longer 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 opportunity 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 doctor, nurse, social worker or a trained counsellor.

Research - clinical trials for Hodgkin lymphoma

Cancer research trials are carried out to try to find new and better treatments for cancer. 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.

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

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",
7TH. ROAD, PRABHAT COLONY,
SANTACRUZ (East),
MUMBAI - 400 055.
PHONE: 91-22-2617 7543 & 91-22-2616 0007
FAX: 91-22-2618 6162,
e-mail: pkrjascap@gmail.com, 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

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

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