Treating Hodgkin’s Lymphoma
A Quick Guide

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

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You can view this information in a larger print on our website.

The stages of Hodgkin’s lymphoma
The stage of the Hodgkin’s lymphoma means whether it is localised or is in more than one area of the body. Your doctor uses the stage to work out the treatment you will need. These are the stages of Hodgkin’s lymphoma:

• Stage 1 means there is Hodgkin’s lymphoma in only 1 group of lymph nodes or lymphoma in 1 body organ only
• Stage 2 means Hodgkin’s lymphoma in 2 or more groups of lymph nodes or an organ and 1 or more group of lymph nodes. In both cases, the 2 sites of lymphoma must be on the same side of the diaphragm
• Stage 3 means Hodgkin’s lymphoma in lymph nodes on both sides of the diaphragm
• Stage 4 means that many groups of lymph nodes contain Hodgkin’s lymphoma and it has spread to body organs such as the liver, bones or lungs

You may need to have more intensive treatment if you have any of the following factors:

• Large areas of lymphoma (bulky disease)
• Lymphoma spreading outside the lymph system
• Symptoms such as heavy sweating at night, a high temperature that comes and goes (often at night), or weight loss.

Hodgkin’s lymphoma that comes back
If your Hodgkin’s lymphoma comes back after it has been treated, this is called recurrent disease. Your doctors will not stage it in the same way as when you were first diagnosed.

Statistics and outlook for Hodgkin’s lymphoma
Outlook means the likely outcome of your disease and treatment. Your doctor may call this your prognosis. With Hodgkin’s lymphoma, the likely outcome depends on how advanced the cancer is when it is diagnosed (the stage). The treatment of
Hodgkin’s lymphoma is often very successful. Many people are cured of their disease. On CancerHelp UK, we have detailed information about the likely outcome of different stages of Hodgkin’s lymphoma. 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. The same type of cancer can grow at different rates in different people. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

Types of treatment for Hodgkin’s lymphoma
When Hodgkin’s lymphoma is diagnosed a team of doctors and other professionals work together to decide on the best treatment for each person. Treatment is usually very successful and many people are cured. How much treatment you need depends on the stage of your lymphoma. And your doctor takes into account whether or not you have B symptoms, the type of Hodgkin’s lymphoma you have, your general health, and your age.

Early stage Hodgkin’s lymphoma (Stage 1 - stage 2A)
If you have early stage disease, you will probably have a short course of chemotherapy, then radiotherapy to the affected lymph nodes.

Advanced stage Hodgkin’s lymphoma (Stage 2B - stage 4)
For advanced stage disease, you are most likely to have chemotherapy with or without steroids. You may also have radiotherapy.

Treating Hodgkin’s lymphoma that has come back
If your disease comes back after treatment (relapses), you may have high dose chemotherapy treatment with bone marrow or stem cell transplant. Or your doctor may suggest more chemotherapy or radiotherapy.

If your lymphoma does not respond
Sometimes Hodgkin’s lymphoma does not respond as well as your doctor would hope. If this happens to you, your doctor may suggest high dose chemotherapy treatment with bone marrow or stem cell transplant. Or they might add in more treatment or change your chemotherapy drugs.

Surgery for Hodgkin’s lymphoma
Surgery is not really used as a treatment for Hodgkin’s lymphoma. We have included it here because 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. Usually the only after effects are a few stitches. It will take a week to 10 days to heal. Then a nurse will take the stitches out.

Radiotherapy for Hodgkin’s lymphoma
Radiotherapy uses high energy rays to kill cancer cells. It may be used when there are Hodgkin’s cells in one or two areas of lymph nodes in one part of the body (stage 1 or 2). Or for advanced Hodgkin’s lymphoma to shrink large lymph nodes. Radiotherapy is usually given before or after chemotherapy treatment.

Having your treatment
You have radiotherapy in the hospital radiotherapy department. Usually, you have treatment once a day from Monday to Friday, with a rest over the weekend. The length of the treatment will depend on the area you are having treated.

On your first visit, you will lie under a machine called a simulator. The doctor uses it to work out where to give the treatment. He or she will make marks on
your skin, to help line up the radiotherapy machine when you have your treatment. The actual treatment only takes a few minutes. Radiotherapy does not make you radioactive.

**Side effects**
The most common side effects during and just after treatment are reddening of the skin in the treatment area, tiredness, and loss of hair in the treatment area. If you are having treatment to your abdomen, you may feel sick or have diarrhoea.

Most people don’t have serious long term effects after radiotherapy. The most common long term effect is darkening of the skin in the treated area. Rarer long term problems include the risk of a second cancer, heart problems, changes to your thyroid gland, infertility and inflammation of the lungs.

**Chemotherapy for Hodgkin’s lymphoma**
Chemotherapy uses anticancer (cytotoxic) drugs to destroy cancer cells. For Hodgkin’s lymphoma you have several chemotherapy drugs together during a course of treatment. Some chemotherapy combinations include a course of steroids. You usually have radiotherapy as well as chemotherapy for Hodgkin’s lymphoma.

A course of chemotherapy is made up of a number of cycles. At the beginning of each cycle you have treatment, usually over 1 to 3 days depending on the drugs you are having. Then you have a break of a few weeks before another cycle begins. You don’t usually have to stay in hospital for treatment.

You may have chemotherapy for Hodgkin’s lymphoma through a vein in your arm. Or you might need a central line. This is a tube that stays in your body so you don’t have to have a needle put in each time you have treatment. The diagram shows a central line.

**High dose chemotherapy**
If you have high dose treatment, it will kill off the cells in your bone marrow that make your blood cells. You will then need a transfusion of either bone marrow or blood stem cells.

**Chemotherapy drugs for Hodgkin’s lymphoma**
There are many different combinations of drugs used to treat Hodgkin’s lymphoma. Your specialist will pick the drug combination which best suits your stage and type of lymphoma.

**Side effects**
All chemotherapy drugs have side effects. Not everyone has the same side effects with the same drug - some people have very few at all. The side effects will go away when your treatment is finished. Common side effects with many drugs are:

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

**Long term side effects**
Chemotherapy can have long term effects on some people’s health. The most common is infertility. If you are young and have not yet had children, your doctor will try to choose drugs that are less likely to cause infertility. Other long term effects are much less common, but include heart disease, damage to the lungs and risk of getting another cancer in the future.
What to ask your doctor about chemotherapy for 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 out patient treatment or will I have to stay in?
- How long will the course of treatment last?
- What are the likely side effects?
- Will I lose my hair?
- Can I have a wig on the NHS?
- Are there long term side effects?
- What is the chance of me having long term side effects?
- Will I still be able to have children after treatment?
- Will I have an early menopause? If so, how will you treat this?
- Can I have sperm banking before I start treatment?
- Can I have egg or embryo freezing before I start treatment?
- What will you do if this treatment doesn’t work?
- Are there any other treatments I could try?
- Are there any clinical trials I might be able to join?

Steroids for Hodgkin’s lymphoma
Steroids are substances made naturally in the body. They can also be made artificially and used as drugs. In Hodgkin’s lymphoma, you may have steroids as part of your chemotherapy treatment. This is because doctors have found that the treatment is more successful when steroids are given along with chemotherapy drugs.

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 quite a few side effects you may notice, including:

- An increase in your appetite
- Having more energy
- Feeling agitated
- Difficulty sleeping
- Indigestion

When 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.

Your doctor will be looking out for other side effects of your steroids. These are raised blood pressure, increased risk of picking up infections, and sugar in the urine. They are unlikely to happen unless you have been taking steroids for some time. They will go away when you stop taking the steroids.

Bone marrow and stem cell transplants for Hodgkin’s lymphoma
If Hodgkin’s lymphoma comes back after treatment your doctor may suggest a stem cell or bone marrow transplant. This is high dose chemotherapy, and sometimes total body radiotherapy, followed by a drip of stem cells or bone marrow. This intensive treatment can get rid of the lymphoma again for many people. Your doctor may also suggest this treatment if your Hodgkin’s lymphoma does not respond to standard treatment.

About bone marrow or stem cell transplants
Stem cells are the cells in our bone marrow that produce blood cells. After high dose chemotherapy the stem cells are destroyed. So you need to have a drip of stem cells or bone marrow into your bloodstream to replace them. The stem cells go from the bloodstream and into the bone marrow. They then start to make blood cells again.

Most people with Hodgkin’s lymphoma have their own marrow or stem cells given back after the high dose treatment. This is called an autologous transplant. It is possible to have a transplant of someone else’s bone marrow or stem cells (an allogeneic transplant). Most often you have the bone marrow or stem cells of a close relative because they are more likely to closely match your own. Doctors are still learning how best to use allogeneic transplants for Hodgkin’s lymphoma.

In the cancer treatments section of CancerHelp UK, there is detailed information about bone marrow and stem cell transplants.
Biological therapy for Hodgkin’s lymphoma

Biological therapies are treatments using substances that occur naturally in the body or that change how these substances work. Various types of biological therapy have been tried for Hodgkin’s lymphoma, sometimes linked to a radioactive molecule. Some therapies are still being tested in clinical trials.

Rituximab for lymphocyte predominant Hodgkin’s lymphoma

People with the rare lymphocyte predominant type of Hodgkin’s lymphoma may have a type of biological therapy called rituximab. It can control the lymphoma for a long time and help people to live longer if the lymphoma doesn’t respond to standard chemotherapy or comes back afterwards. The side effects of rituximab can include flu like symptoms, feeling sick, diarrhoea, an itchy rash, changes in blood pressure, and feeling weak and tired.

If Hodgkin’s lymphoma comes back

If Hodgkin’s lymphoma comes back it may still be possible to get rid of it again completely. This will mostly depend on:

- How well further treatment works for your type of Hodgkin’s lymphoma
- The treatment you have already had
- Your general health and level of fitness

Even if your lymphoma can’t be cured, you will be able to have treatment to shrink the enlarged lymph nodes. Treatment may include radiotherapy, chemotherapy, or intensive treatment with bone marrow or stem cell transplant. People who have the rare type of lymphocyte predominant Hodgkin’s lymphoma may have the biological therapy rituximab (Mabthera).

Your feelings

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 getting some 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.

Follow up for Hodgkin’s lymphoma

After your treatment has finished, you will have regular check ups. Your doctor will examine you and you may have a blood test at each appointment. You may also have CT scans, PET-CT scans or X-rays from time to time. Your doctor will ask how you are feeling and whether you have any new symptoms. If you are worried or notice any new symptoms between appointments, let your doctor know straight away.

How often and how long for?

Your check ups will continue for several years. At first they will be every 3 months. If all is well, you will go less and less often. Some specialists stop follow up appointments and discharge you after 3 years. Your doctor may want you to carry on having check ups because of the small risk of getting another cancer. They may suggest that you join a regular screening programme - for example, women who had radiotherapy to the chest for Hodgkin’s before the age of 35 should have regular breast cancer screening.

If you are worried

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 you could try talking to someone at a cancer support group. It is quite common nowadays for people to have counselling after cancer treatment. Look in the coping with cancer section of CancerHelp UK for more information.

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
What to ask your doctor about treatment for Hodgkin’s lymphoma

- What can you tell me about my Hodgkin’s lymphoma?
- What stage is it?
- What sort of treatment do you recommend?
- What is the aim of the treatment?
- Is there a choice of treatment?
- How long will treatment last?
- Will I have to have any surgery, radiotherapy or chemotherapy?
- What side effects will there be?
- Will I be able to have children after chemotherapy or radiotherapy?
- Can I bank sperm (eggs) before I have treatment?
- Is there anything I can do to help reduce the side effects?
- When will you know how well the treatment has worked?
- What will you be able to tell me?
- How often will you see me after treatment has finished?
- What should I do if I am worried between appointments?
- Will I be able to have more treatment if the Hodgkin’s lymphoma comes back?
- Are there any experimental treatments that might help me?
- Are there any clinical trials I could take part in?
For more information, visit our website http://www.cruk.org/cancerhelp

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 trials in the UK. Our information is based on the best current scientific evidence and reviewed regularly by leading clinicians and experts in health and social care.

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 October 2011. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. Copyright Cancer Research UK 2011. Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and in the Isle of Man (1103)