It is devastating to hear that your child has cancer, and at times it can feel overwhelming, but there are many healthcare professionals and support organisations to help you through this difficult time. Understanding more about the cancer your child has, and the treatments that may be used, can often help parents to cope. We hope you find the information here helpful. Your child’s specialist will give you more detailed information and, if you have any questions, it is important to ask the specialist doctor or nurse who knows your child’s individual situation.

This factsheet is published in conjunction with CCLG’s booklet entitled: ‘Children and Young People with Cancer: A Parent’s Guide’.

Hodgkin lymphoma

Hodgkin lymphoma is a type of blood cancer. It can affect children at any age but is more common in older teenagers and young adults. Each year in the UK, there are around 70 children aged 0-14 years, 120 young people aged 15-19 years, and 180 young people aged 20-24 years, diagnosed with Hodgkin lymphoma.

More children than ever are surviving childhood cancer. There are new and better drugs and treatments, and we can now also work to reduce the after-effects of having had cancer in the past.

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What is Hodgkin lymphoma?

Hodgkin lymphoma is a type of cancer that occurs in the lymphatic system. There are two main types of Hodgkin lymphoma: classical Hodgkin lymphoma, which affects 95% of patients, and Lymphocyte Predominant Hodgkin Lymphoma (LPHL), which only affects 5% of patients. This information is about classical Hodgkin lymphoma, but it includes a short section about LPHL.

The lymphatic system

The lymphatic system is part of the immune system, the body’s natural defence against infection and disease.

The lymphatic system is made up of the bone marrow, thymus, spleen, and lymph nodes (or lymph glands). Lymph nodes are connected by a network of tiny lymphatic vessels that contain lymph fluid. Lymphomas can start anywhere in the lymphatic system, but Hodgkin Lymphoma is most likely to start in the lymph nodes in the neck. The other areas where lymph node

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nodes are likely to swell are above the collar bone, the armpit, the groin and inside the chest. Glands can swell in these areas as part of the body’s response to infection, not just cancer, which is why a biopsy is needed to diagnose lymphoma.

The number of lymph nodes varies from one part of the body to another. In some parts of the body, there are very few lymph nodes, whereas under your arm there may be 20-50.

There are two main types of lymphoma: non-Hodgkin lymphoma (NHL) and Hodgkin lymphoma (HL). Although these are both types of lymphoma, there are differences between them, which means they need different treatment.

Causes

The exact cause of Hodgkin lymphoma is not known. In most people that develop Hodgkin lymphoma, no cause is found. However, there is increasing evidence infections, such as the virus that causes glandular fever, may play a part in the development of Hodgkin lymphoma, especially in childhood. Poor immunity may also be a risk factor for developing the disease. Very rarely, more than one member of a family may develop Hodgkin lymphoma but it is not inherited from parents and you cannot catch it from another person.

Signs and symptoms

The first sign of Hodgkin lymphoma is usually a painless swelling of one gland, or a group of lymph glands, which continues for some weeks or even months. The first glands that are likely to be affected are in the neck or above the collarbone, most often only on one side. However, it’s important to remember that children’s glands can also become swollen when they have a common infection that causes a sore throat or a cold. If glands in the chest are affected, this can cause a cough or breathlessness. This is caused by the pressure the glands exert on the airways. Sometimes, a child with Hodgkin lymphoma may have a high temperature (fever), night sweats, weight loss or itchy skin.

How Hodgkin lymphoma is diagnosed

As lymph glands can swell for lots of reasons, a biopsy is carried out to diagnose Hodgkin lymphoma. A biopsy is when a swollen lymph gland is removed and the cells are looked at under a microscope. It’s a small operation which is usually done under a general anaesthetic. Sometimes only a small part of the lymph gland has to be removed, which can be done under a local anaesthetic.

If Hodgkin lymphoma is diagnosed after the biopsy, further tests are carried out to find out the exact size and position of the lymphoma, and to see whether it has spread beyond the original area. These tests include x-rays, blood tests, CT, MRI and PET scans.

The tests carried out are called staging tests. Any tests and investigations your child needs will be explained to you. Our section on children’s cancers gives details of what the tests and scans involve.

Staging

The stage of Hodgkin lymphoma describes the size and position of the cancer and whether it has spread. Staging is very important because this guides how much treatment you will need. The number of cycles of chemotherapy you receive is decided by the stage. The staging system for Hodgkin lymphoma is as follows:

Stage 1
Only one group of lymph nodes is affected and the lymphoma is only on one side of the diaphragm (the sheet of muscle under the lungs that controls breathing).

Stage 2
Two or more groups of lymph nodes are affected, but they are only on one side of the diaphragm.

Stage 3
The lymphoma is in lymph nodes both above and below the diaphragm.

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

As well as giving each stage a number, doctors also use a letter code - either A, B, or E:

- A means your child has no symptoms.
- B means your child has one or more of the following symptoms: a fever, night sweats or significant weight loss.
- E means that the lymphoma has grown from the lymph gland to extranodal tissue (tissue in places outside the lymph nodes).

A number and letter is used in the staging of every child with Hodgkin lymphoma. This helps the doctor decide on a treatment plan for your child.

Treatment

Treatment is chemotherapy in all children and some children also need radiotherapy. The type and amount of treatment given depends on the stage of the disease when it is diagnosed. Your child’s doctor will discuss the treatment options with you.
Chemotherapy
This is the main treatment and all children receive chemotherapy. The number of months/cycles of chemotherapy you will need is based on the stage of disease. Low stage patients receive less and high stage receive more cycles of chemotherapy which means we can keep the cure rates high for all patients.

Radiotherapy
Radiotherapy is used in less than half of all children and only recommended when it’s really needed. Usually two cycles of chemotherapy are given and then a PET scan is done. If the PET scan is clear, then radiotherapy is usually not needed but if the PET scan shows active cancer still present then it usually will be recommended.

Side effects of treatment
Treatment for Hodgkin lymphoma can cause side effects, and your child’s doctor will discuss these with you before the treatment starts. Any possible side effects will depend on the particular treatment being used and the part of the body that is being treated. Some general side effects of chemotherapy that can occur during treatment include:
- feeling sick (nausea) and being sick (vomiting)
- hair loss
- low blood count which can lead to an increased risk of infection, bruising and bleeding
- tiredness

Changes to your child’s sense of taste and changes in their bowel may also happen. If your child has side effects from the treatment it is important to discuss them with your doctor or nurse. They may be able to help reduce them.

Late side effects of treatment
The cure rate for Hodgkin lymphoma is very high, which means some children may develop side effects many years after treatment. The chance of developing late side effects depends on where the original tumour was, how far it spread, and the type of treatment your child had.

The chemotherapy used in children has been developed to have minimal long term side effects. Long term side effects may occur more often after radiotherapy. Chemotherapy and especially radiotherapy increase the risk of developing other cancers later in life. Possible late effects include effects on normal organs such as the heart, kidneys and lungs and a low risk of reduced fertility. Teenage boys who are diagnosed after puberty should have the option of sperm banking before treatment starts. In this situation, sperm can be stored for possible use in later years. Your child’s doctor or nurse will explain more about any possible late side effects.

Clinical trials
Many children have their treatment as part of a clinical research trial. Trials aim to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. The aim of treatment for Hodgkin lymphoma is to cure the cancer with the fewest possible short and long-term side effects. This is particularly important in childhood Hodgkin lymphoma where cure rates are high. It is important to get the balance right between curing the cancer and having the lowest risk of long-term side effects.

If appropriate, your child’s medical team will talk to you about taking part in a clinical trial and will answer any questions you may have. Written information is often provided to help explain things. Taking part in a research trial is completely voluntary, and you’ll be given plenty of time to decide whether it’s right for your child.

Treatment guidelines
Sometimes, clinical trials are not available for your child’s tumour. This may be because a recent trial has just finished, or because the tumour is very rare. In these cases, you can expect your doctors and nurses to offer treatment which is agreed to be the most appropriate, using guidelines which have been prepared by experts across the country. The Children’s Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

Follow-up care
About 90% of children who develop Hodgkin lymphoma are cured. When your child completes treatment, they will then go into a follow-up phase, seeing doctors and nurses in out-patient clinics usually for around five years. Clinic visits will be every 3-4 months to start with and there will be occasional scans, x-rays, and blood tests done for several years after completing treatment. If the cancer comes back, a different course of treatment can be given. If you have specific concerns about your child’s condition and treatment, it’s best to discuss them with your child’s doctor, who knows the situation.

Lymphocyte predominant Hodgkin lymphoma (LPHL)
This is a rare type of Hodgkin lymphoma that affects around 5% of patients. LPHL usually grows at a slower rate than classical Hodgkin lymphoma and normally requires less intensive treatment. Young people with LPHL may have a single swollen gland or group of swollen glands in one area only, such as the neck or groin. The swollen gland often grows very slowly and may be present for many months before a biopsy and diagnosis happens. The biopsy and staging tests will be carried out as with classical Hodgkin lymphoma. The treatment given will depend on the stage of the disease, but most patients are diagnosed with an early stage of the disease.

LPHL is usually treated with surgery or low-dose chemotherapy. It may return many years after treatment, and further treatment may be required, but it is rarely a life-threatening condition. In rare cases, patients have advanced LPHL and receive more intensive chemotherapy. There is also a link between LPHL and developing a more aggressive non-Hodgkin lymphoma.
Your feelings
As a parent, the fact that your child has cancer is one of the worst situations you can be faced with. You may have many emotions, such as fear, guilt, sadness, anger and uncertainty. These are all normal reactions and are part of the process that many parents go through at such a difficult time. It’s not possible to address in this factsheet all of the feelings you may have.

However, the CCLG booklet ‘Children & Young People’s Cancer; A Parent’s Guide’, talks about the emotional impact of caring for a child with cancer and suggests sources of help and support.

Your child may have a variety of powerful emotions throughout their experience of cancer. The Parent’s Guide discusses these further and talks about how you can support your child.

References
This factsheet has been compiled using information from a number of reliable sources, including:


USEFUL ORGANISATIONS

Children’s Cancer and Leukaemia Group (CCLG)
www.cclg.org.uk

CLIC Sargent
www.clicsargent.org.uk
CLIC Sargent offers practical support to children and young people with cancer or leukaemia, and to their families.

Macmillan Cancer Support
www.macmillan.org.uk
Offers support and advice to those affected by cancer.

Lymphoma Association
www.lymphomas.org.uk
The Lymphoma Association provides information and emotional support to people with lymphoma and their families, carers and friends.

With thanks to Dr Stephen Daw, Consultant Paediatric Oncologist at UCLH in London and Chair of the CCLG Hodgkin Lymphoma Interest Group, who reviewed this factsheet on behalf of the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer.

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