Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Hodgkin lymphoma in children

An information guide for parents and families

The purpose of this guide is to give information about Hodgkin lymphoma to help you understand more about the type of cancer your child has.

Information in this guide should be used to support professional advice specific to your child's diagnosis. If you have any questions, it is important to ask your child's medical team.

What is lymphoma?

Lymphoma is a cancer which develops when a type of white blood cell called a lymphocyte grows abnormally.

Lymphocytes help fight infection as part of the immune system and are carried round the body in the lymphatic system. This is a complex system made up of the bone marrow, thymus, spleen, and lymph nodes throughout the body. The lymph nodes are connected by a network of tiny lymphatic vessels.

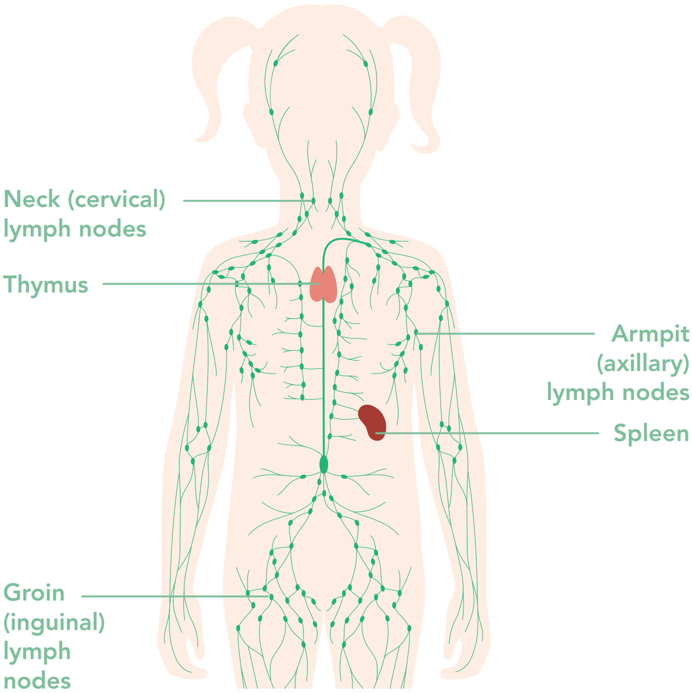
Lymph nodes are also known as lymph glands, and the ones that you're most likely to notice are those in the neck, armpit and groin. The number of lymph nodes varies from one part of the body to another.

There are two types of lymphoma depending on which type of lymphocyte is affected:

- Hodgkin lymphoma
- Non-Hodgkin lymphoma

This factsheet is about Hodgkin lymphoma only. A separate one is available for non-Hodgkin lymphoma.

The lymphatic system: A network of tissues and organs that help protect us from infection and disease



What is Hodgkin lymphoma?

Hodgkin lymphoma is a type of blood cancer that occurs in the lymphatic system. 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 diagnosed with Hodgkin lymphoma.

There are two main types of Hodgkin lymphoma:

- **classical Hodgkin lymphoma** – affects 95% of patients
- **Lymphocyte Predominent Hodgkin Lymphoma (LPHL)** – affects 5-10% of patients.

This information is about classical Hodgkin lymphoma, but it includes a short section about LPHL.

Causes of Hodgkin lymphoma

In most people that develop Hodgkin lymphoma, no cause is found. Some factors such as infection with the Epstein-Barr virus (EBV) that causes glandular fever; having a medical condition or treatment that weakens your immune system, can play a part in developing Hodgkin lymphoma during childhood.

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. It is important to remember that nothing you have done has caused the cancer.

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.

Lymphomas can start anywhere in the lymphatic system, but Hodgkin lymphoma is most likely to start in the lymph nodes in the neck causing swelling above the collar bone, under the armpits, in the chest or further down in the abdomen or groin. Glands can swell in these areas as part of the body's response to any infection.

If glands in the chest are affected, this can cause a cough or breathlessness. Sometimes, a child with Hodgkin lymphoma may have a high temperature (fever), night sweats, weight loss, persistent itchy skin, and tiredness.

How it is diagnosed

As lymph glands can swell for lots of reasons, a biopsy is done to find the cause. Part, or all, of a swollen lymph gland is removed so that the cells can be examined in a laboratory. This is a small operation usually done under general 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. This is known as staging. Any tests and investigations your child needs will be explained to you.

Staging of Hodgkin lymphoma in children

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site.

STAGE 1	STAGE 2	STAGE 3	STAGE 4
One group of lymph nodes is affected and the lymphoma is on one side of the diaphragm (the sheet of muscle under the lungs that controls breathing).	Two or more groups of lymph nodes are affected, but they are only on one side of the diaphragm.	The lymphoma is in lymph nodes both above and below the diaphragm.	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 tissue outside the lymph nodes (extranodal tissue)

Treatment

Treatment for Hodgkin lymphoma has a very good success rate and about 90% of children are cured. The main treatment for Hodgkin lymphoma is chemotherapy. Some children will also need radiotherapy. Your child's treatment will depend on the stage of the disease. Your child's doctor will discuss the treatment options with you.

Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. All children receive chemotherapy. The length of treatment depends on the stage of the disease.

Radiotherapy

Radiotherapy is needed in less than half of all children. 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.

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 side effects will depend on the part of the body that's being treated and what treatment is being used.

Most side effects are short-term and gradually disappear once treatment stops. Side effects can include:
- feeling sick (nausea) and being sick (vomiting)
- temporary hair loss
- tiredness
- low blood count leading to an increased risk of infection and bruising and bleeding (sometimes blood and/or platelet transfusions are needed)
- a sore mouth and tummy
- diarrhoea

Radiotherapy can make your child feel tired, and the skin in the area that's being treated may go red or get darker.

Clinical trials

Many children have their treatment as part of a clinical research trial. Clinical trials are carried out to try to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. Clinical trials mean there are now better results for curing children's cancers compared with just a few years ago.

Your child's medical team will talk to you about taking part in a clinical trial and will answer any questions you have. Taking part in a research trial is completely voluntary, and you'll be given plenty of time to decide if it's right for your child. You may decide not to take part, or you can withdraw from a trial at any stage. Your child will still receive the best treatment available.

National treatment guidelines

Sometimes, clinical trials are not available for your child's cancer. In this case, your doctors will offer the most appropriate treatment, using guidelines which have been agreed by experts across the UK. Children's Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

Donating to a tissue bank

Hodgkin lymphoma is a rare disease and more research is needed to help doctors develop better treatment for the future. Your child's hospital team will offer you the opportunity to anonymously donate tissue left over from tests carried out, for example, a biopsy or bone marrow test, to the tissue bank. This sample of tissue can be used by scientists to learn more about Hodgkin lymphoma and how best to treat it. This is voluntary, and you will have plenty of time to decide if you wish to take part.

Late side effects

Months or years later some children may develop late side effects from the treatment they have had. These may include a reduction in bone growth, a change in the way the heart, lungs and kidneys work, a risk of infertility and a small increase in the risk of developing another cancer in later life. For more information please visit www.cclg.org.uk/living-beyond-cancer

Your child's doctor or nurse will talk to you about any possible late side effects and will keep a close eye on possible long-term side effects in follow-up clinics.

Lymphocyte predominant Hodgkin lymphoma (LPHL)

Lymphocyte predominant Hodgkin lymphoma (LPHL) 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 are carried out in the same way as classical Hodgkin lymphoma.

The treatment given will depend on the stage of the disease. LPHL is usually treated with surgery to remove the affected gland which can cure it, or low-dose chemotherapy. It may return many years later, 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.

Follow-up care

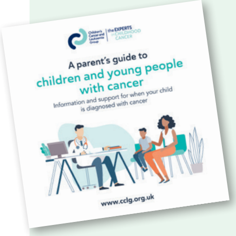
Once treatment has finished, the doctors will monitor your child closely with regular appointments to be sure that the cancer has not come back and there are no complications. After a while, you will not need to visit the clinic so often.

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 in detail.

Your feelings

It's devastating to hear that your child has cancer and you may feel overwhelmed, but there are many professionals and organisations to help you through this difficult time. You may have many feelings, such as fear, guilt, sadness, anger, and uncertainty. These are all normal and are part of the process that many parents go through.

It's not possible to address in this guide all of the feelings you may have. However, the CCLG booklet 'A parent's guide to children and young people with cancer', 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.



A parent's guide to children and young people with cancer
Information and support for when your child is diagnosed with cancer
www.cclg.org.uk

The CCLG booklet 'A parent's guide to children and young people with cancer' is available FREE of charge from your child's hospital

All CCLG booklets and leaflets can be downloaded or ordered from our website:

www.cclg.org.uk/publications

i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download.
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families
www.younglivesvscancer.org.uk

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

Lymphoma Action provides information and support to people with lymphoma and their families, carers and friends.
www.lymphoma-action.org.uk

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally,to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

If you have any comments on this factsheet, please contact us at publications@cclg.org.uk