



Non-Hodgkin lymphoma in children

An information guide for parents and families

The purpose of this guide is to give information about non-Hodgkin lymphoma (NHL) 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.

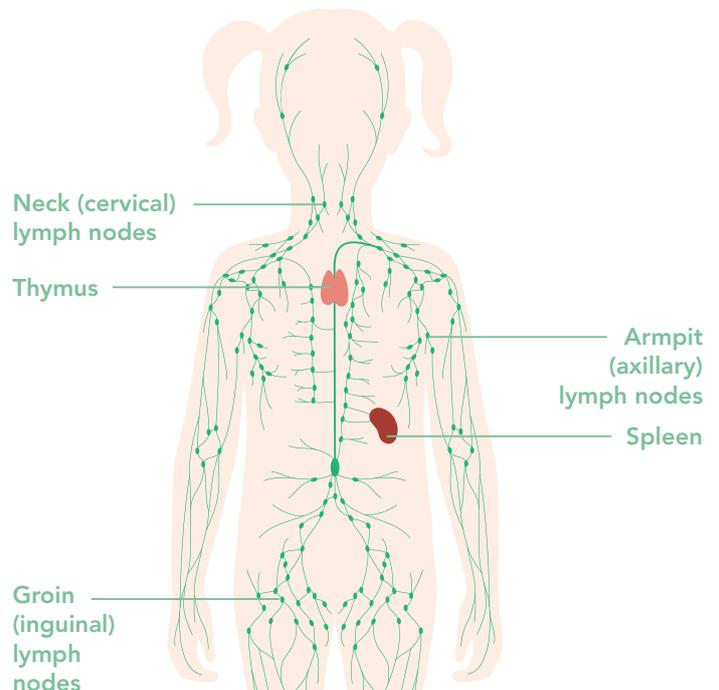
Lymph nodes are also known as lymph glands, and the ones that you're most likely to notice are those in the neck, armpit and groin. The number of lymph nodes varies from one part of the body to another.

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

- Hodgkin lymphoma
- Non-Hodgkin lymphoma

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

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



What is non-Hodgkin lymphoma?

Non-Hodgkin lymphoma is a type of blood cancer. About 80 children of all ages develop non-Hodgkin lymphoma (NHL) in the UK each year. It is more common in boys than girls.

The four main types of NHL are:

- **Lymphoblastic lymphoma** - usually affects lymph nodes and thymus in the chest
- **Burkitt lymphoma** - often involves lymph nodes in the stomach area
- **Diffuse large B cell lymphoma (DLBCL)** - often involves lymph nodes in the stomach area
- **Anaplastic large cell lymphoma (ALCL)** - can affect almost any body tissue including the skin

Occasionally, NHL can develop in unusual places outside the lymph nodes. This is called extranodal lymphoma.

Causes of NHL

We don't know what causes NHL but there is research going on all the time to try to find out. It is important to remember that nothing you have done has caused the cancer.

Signs and symptoms

The first sign of NHL is usually a lump somewhere in the body, which is caused by swollen lymph nodes. This can cause different symptoms, depending on where the swollen lymph nodes are.

If glands in the abdomen are affected, this may cause a feeling of being full after meals and some tummy pain. Other symptoms of NHL include a high temperature (fever), tiredness, weight loss, and loss of appetite. In a few children, lymphoma cells may be found in the bone marrow or in the fluid around the spinal cord (cerebrospinal fluid).

How it is diagnosed

A variety of tests and investigations may be needed to diagnose NHL. Part, or all, of a swollen lymph gland may be removed so that the cells can be examined in the laboratory (biopsy). This involves a small operation that is usually done under a general anaesthetic. Tests such as x-rays, ultrasound scans, MRI scans, CT scans, blood tests and bone marrow samples may be carried out to find out the extent of the disease. This is known as staging. Any tests and investigations that your child needs will be explained to you.

Staging of non-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. The type of treatment your child receives depends on the stage of the disease. A simplified version of the stages of NHL is given below:

STAGE 1

One group of lymph nodes is affected, or there's a single extranodal tumour.

STAGE 2

Two or more groups of nodes are affected, or there is a single extranodal tumour that has spread to nearby lymph nodes; or there are two single extranodal tumours, but only on one side of the diaphragm (the sheet of muscle under the lungs, which plays a large part in our breathing).

STAGE 3

There's lymphoma on both sides of the diaphragm (either in two or more groups of nodes) or there are two single extranodal tumours or the lymphoma is affecting the chest.

STAGE 4

The lymphoma has spread beyond the lymph nodes to other organs of the body such as the bone marrow or nervous system.

Treatment

Treatment for NHL has a very good success rate and many children are cured. Chemotherapy is the most important treatment for children with NHL. Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

Often a combination of drugs is used and treatment may last a number of months or years. The treatment will be planned according to your child's particular type of NHL and the stage of the disease. Your child's doctor will discuss the treatment options with you.

Lymphoblastic lymphoma is similar to lymphoblastic leukaemia and is treated using current leukaemia treatments which last 2-3 years.

Burkitt lymphoma and **DLBCL** are treated with 4–6 courses of intensive chemotherapy. Some patients will also receive rituximab, an anti-CD20 antibody that kills NHL cells by a biological method.

ALCL is treated with six courses of intensive chemotherapy.

NHL can sometimes affect the brain and spinal cord. To stop this, chemotherapy may be injected directly into the fluid around the spinal cord. This is called intrathecal chemotherapy.

Very rarely, radiotherapy is also necessary. Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells.

High-dose chemotherapy with a bone marrow transplant is sometimes used if the NHL comes back after initial treatment.

Side effects of treatment

Treatment for NHL 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. Side effects can include:

- feeling sick (nausea) and being sick (vomiting)
- a sore mouth and tummy
- temporary hair loss
- a low blood count leading to an increased risk of infection and bruising and bleeding (sometimes blood and/or platelet transfusions are needed)
- tiredness
- diarrhoea

Clinical trials

Many children have their treatment as part of a clinical research trial. Clinical trials are carried out to try to find new and better treatments. 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 then receive the best standard treatment available.

National 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, your doctors will offer the most appropriate treatment, using guidelines which have been agreed by experts across the country. Children's Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

Donating to a tissue bank

NHLs are rare diseases 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 then be used by scientists to learn more about NHL 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. It is important to understand that not all side effects will happen to all patients. Please visit www.cclg.org.uk/Life-after-childhood-cancer for more information.

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.

Follow-up care

Around 80% of the children who get NHL recover completely. The chances of successful treatment depends on the specific type, stage and grade of lymphoma. 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 is devastating to hear that your child has cancer and may feel overwhelming but there are many professionals and organisations to help you through this difficult time. 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.



USEFUL ORGANISATIONS

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

Publishes a variety of resources related to childhood cancer. These are available to order or download free of charge from the website.

Young Lives vs Cancer
www.younglivesvscancer.org.uk

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 Action
www.lymphoma-action.org.uk

Provides information and emotional support to people with lymphoma and their families, carers and friends.

Blood Cancer UK
www.bloodcancer.org.uk

Funds research and provides information and support to those affected by blood cancers.



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



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Patient Information Forum

With thanks to Dr Simon Bomken, Honorary Consultant Paediatric Oncologist at The Great North Children's Hospital and Chair of the CCLG NHL Special Interest Group, Dr Mary Taj, Consultant Paediatric Oncologist at the Royal Marsden and Chair of NCRI Paediatric NHL group and Amos Burke, Consultant Paediatric Oncologist at Addenbrooke's Hospital and member of the CCLG NHL Special Interest Group, who reviewed this factsheet on behalf of the CCLG Information Advisory Group, comprising multiprofessional experts in the field of children's cancer.

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. This will cost £3 plus a standard rate message.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that this information is accurate and up to date at the time of printing. CCLG does not accept any responsibility for information provided by third parties including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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