Non-Hodgkin lymphoma (NHL)

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.

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.

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’.

Non-Hodgkin lymphoma (NHL)
The lymphatic system is part of the immune system, the body’s natural defence against infection and disease. 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; in some parts there are very few, whereas under your arm there may be 20-50 nodes.

Cancers that start in the lymphatic system are called lymphomas. There are two main types of lymphoma:

- Hodgkin lymphoma
- Non-Hodgkin lymphoma

Although they’re both types of lymphoma, there are differences between them, which means they need different treatment.

There are two main types of NHL. B-cell NHL usually involves the lymph nodes in the abdomen and intestines, but may involve nodes in the head and neck. T-cell NHL usually affects lymph nodes in the chest.
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. We have more information about what the tests and scans involve.

**Staging**
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:

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>One group of lymph nodes is affected, or there's a single extranodal tumour.</th>
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</thead>
<tbody>
<tr>
<td>Stage 2</td>
<td>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).</td>
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<tr>
<td>Stage 3</td>
<td>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.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>The lymphoma has spread beyond the lymph nodes to other organs of the body such as the bone marrow or nervous system.</td>
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**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.

It is common for a combination of drugs to be 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.

B-cell NHL is treated with 4–8 courses of intensive chemotherapy.

T-cell NHL treatment is less intensive but more prolonged lasting 2-3 years. Your child’s doctor will discuss the treatment options with you.

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.

Rituximab is an anti CD20 antibody that kills NHL cells by a biological method and is also used in some patients.

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

High-dose chemotherapy with a bone marrow transplant is sometimes used (again, very rarely) if the NHL comes back (recurs) after initial treatment.

**Side effects of treatment**
Treatment for NHL can cause different side effects, and your child’s doctor will discuss these with you before the treatment starts. Any possible side effects will depend on the part of the body that’s being treated and what treatment is being used. Some children have just a few side effects, while others experience more. Side effects can include:

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

**Late side effects**
Months or years later some children will develop late side effects from the treatment they have had. These include a possible reduction in bone growth, a change in the way the heart, lungs and kidneys work, and a small increase in the risk of developing another cancer in later life. After treatment with chemotherapy, some children - particularly boys - may become infertile. Older boys, and their parents, should be aware of the option of sperm banking. In this situation, sperm can be stored for possible use in...
later years. 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. We have more detailed information about these late side effects.

Clinical trials
Many children have their treatment as part of a clinical research trial. Cancer research trials are carried out to try to find new and better treatments for cancer. 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. Written information is provided to help explain things.

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.

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 is an important organisation which helps to produce these guidelines.

Follow-up care
Once treatment has finished, the doctors will monitor your child closely with regular appointments in the hospital outpatient department. Over 80% of the children who get NHL recover completely. The chances of successful treatment depend on the specific type, stage and grade of lymphoma. Your child’s doctor can discuss these details with you.

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
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.maccmillan.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.

Leukaemia & Lymphoma Research  www.beatingbloodcancers.org.uk
Supports research into the treatment of leukaemia and other related blood disorders in both children and adults.
Children’s Cancer and Leukaemia Group is a leading children’s cancer charity and the UK and Ireland’s professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

With thanks to Dr Mary Taj, Consultant Paediatric Oncologist at the Royal Marsden and Chair of the CCLG NHL Interest Group, who reviewed this factsheet on behalf of the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer.

CCLG makes every effort to ensure that information provided is accurate and up-to-date at the time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in the publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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