Rhabdomyosarcoma in children

This fact sheet is about rhabdomyosarcoma in children. You may find it helpful to read it alongside the Macmillan/CCLG booklet 
A parent’s guide to children’s cancers, which contains more information about cancers in children, their diagnosis and treatment, and the support services available.

We hope this fact sheet answers your questions. If you have any further questions, you can ask a nurse or doctor involved in your child’s treatment.

If you’d like to discuss this information with our cancer support specialists, call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you’re hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk

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Sarcomas

Sarcomas are rare types of cancer that develop in the supporting tissues of the body, such as bone, muscle or cartilage. There are two main types of sarcomas:

Soft tissue sarcomas can develop in muscle, fat, blood vessels, or in any of the other tissues that support, surround and protect the organs of the body.

Bone sarcomas can develop in any of the bones of the skeleton.
Rhabdomyosarcoma

Fewer than 60 children are diagnosed with rhabdomyosarcoma in the UK each year. Most of them are younger than 10 years old. It's more common in boys than girls.

Rhabdomyosarcoma is the most common of the soft tissue sarcomas in children. These tumours develop from muscle or fibrous tissue and can grow in any part of the body.

The most common areas of the body to be affected are around the head and neck, the bladder, or the testes. Sometimes tumours are also found in a muscle or a limb, in the chest or in the abdominal wall. If the tumour is in the head or neck region, it can occasionally spread into the brain or the fluid around the spinal cord.

Causes of rhabdomyosarcoma

The causes of rhabdomyosarcoma are unknown. Research into possible causes of this disease is going on all the time. Children with certain rare genetic disorders, such as Li-Fraumeni syndrome, have a higher risk of developing rhabdomyosarcoma.

Signs and symptoms

The signs and symptoms will depend on the part of the body that's affected by the rhabdomyosarcoma. The most common sign is a swelling or lump.

- If the tumour is in the head area, it can sometimes cause a blockage (obstruction) and a discharge from the nose or throat. Occasionally, an eye may appear swollen and protruding.
- If the tumour is in the abdomen (tummy), your child may have discomfort in the abdomen and difficulty going to the toilet.
- If the tumour is in the bladder, your child may have blood in the urine and difficulty passing urine.

How it is diagnosed

A variety of tests and investigations may be needed to diagnose a rhabdomyosarcoma. A small operation may be needed to remove a sample from the tumour to be looked at under a microscope. This is called a biopsy. It's usually done under a general anaesthetic.

Various tests may be done to check the exact size of the tumour, and whether it has spread to any other part of the body. These may include:

- a chest x-ray to check the lungs
- an ultrasound
- CT or MRI scans
- blood and bone marrow tests.

Any tests and investigations that your child needs will be explained to you. The booklet A parent's guide to children's cancers gives details of 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. Knowing the particular type and stage of the cancer helps the doctors decide on the most appropriate treatment.

Most patients are grouped depending on whether the cancer is found in only one part of the body (localised disease), or if it has spread from one part of the body to another (metastatic disease). The place in the body where the rhabdomyosarcoma started is considered in the staging system.

Your child's doctor will explain to you the stage of your child's cancer.

Treatment

Rhabdomyosarcomas are rare tumours and should be treated at specialist centres.

Treatment depends upon the size of the tumour, its position within the body, and whether it has spread. Treatment of rhabdomyosarcoma usually includes
surgery, radiotherapy or chemotherapy, or a combination of these treatments.

**Surgery**
If at all possible, surgery will be used to remove the tumour. Chemotherapy, using a combination of drugs, is often given before surgery to shrink the tumour. Radiotherapy may also be given to the area of the tumour, particularly if it cannot be completely removed by surgery.

**Chemotherapy**
If the tumour cannot be removed with surgery, treatment will usually involve a combination of chemotherapy and radiotherapy. Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells and is usually given every three weeks. It may be given to shrink the tumour before surgery, or with radiotherapy when the tumour can't be removed by surgery. The drugs used and the length of treatment depends on the type and stage of the rhabdomyosarcoma.

**Radiotherapy**
Radiotherapy treats cancer by using high-energy rays, which destroy the cancer cells while doing as little harm as possible to normal cells. It's given to the area where the rhabdomyosarcoma occurs.

**Side effects of treatment**
Treatment for rhabdomyosarcoma often causes side effects, and your child’s doctor will discuss this with you before treatment starts. Any possible side effects will depend on the particular treatment being given, and the part of the body that's being treated.

Chemotherapy can make your child feel better by relieving the symptoms of the cancer, but it can sometimes have side effects such as feeling sick (nausea) and being sick (vomiting), hair loss, an increased risk of infection, bruising and bleeding, tiredness and diarrhoea.

**Late side effects**
A small number of children may develop side effects many years after their treatment for a rhabdomyosarcoma. Longer-term side effects depend on the type of treatment used, and may include a possible reduction in bone growth, infertility, a change in the way the heart and the kidneys work, and a slight increase in the risk of developing another cancer in later life.

Your child’s doctor or nurse will talk to you about any possible late side effects. There is more detailed information about these late side effects in the booklet *A parent’s guide to children’s cancers*.

**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. Specialist doctors carry out trials for children's cancer. If appropriate, 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.

Before any trial is allowed to take place it must be approved by an ethics committee, which protects the interests of the patients taking part.

If you decide to take part in a trial, your doctor or a research nurse must discuss the treatment with you so that you understand the trial and what it means for your child to take part. You may decide not to take part, or you can withdraw from a trial at any stage. You will then receive the best standard treatment available.
Follow-up
After treatment, the doctors will regularly check your child 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 their 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 fact sheet all of the feelings you may have. However, the Macmillan/CCLG booklet *A parent’s guide to children’s cancers* 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 this further and talks about how you can support your child.

Our booklet *Peppermint Ward* is a storybook for younger children with cancer. It looks at the issues that they and their family may face, and helps them to explore their feelings.

Useful organisations
**Children’s Cancer and Leukaemia Group (CCLG)**
University of Leicester, 3rd Floor, Hearts of Oak House, 9 Princess Road West, Leicester LE1 6TH
Tel 0116 249 4460
Email info@cclg.org.uk
[www.cclg.org.uk](http://www.cclg.org.uk)
Coordinates research and care for children and their parents. There are 21 CCLG specialist centres for the treatment of childhood cancer and leukaemia, covering all areas of the UK and Ireland (there’s a map of the centres on the website). Has information about the CCLG, childhood cancer and leukaemia.

**CLIC Sargent**
Griffin House, 161 Hammersmith Road, London W6 8SG
Tel 0300 330 0803
Email info@clicsargent.org.uk
[www.clicsargent.org.uk](http://www.clicsargent.org.uk)
Offers practical support to children and young people with cancer or leukaemia, and to their families.

**European Paediatric Soft Tissue Sarcoma Group (EpSSG)**
[epssg.cineca.org](http://epssg.cineca.org)
A group that coordinates clinical trials for children with rhabdomyosarcoma.
Related Macmillan information

- A parent’s guide to children’s cancers
- Katie’s Garden (a storybook for primary school-age children about a girl’s experience of cancer)
- Peppermint Ward – a story about children with cancer
- Understanding cancer research trials (clinical trials)
- Understanding chemotherapy
- Understanding radiotherapy

For copies of this related information call free on 0808 808 00 00, or see it online at macmillan.org.uk

Our website click4tic.org.uk has cancer information written specifically for young people. Get advice and support, and connect with other young people affected by cancer.

This fact sheet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

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This fact sheet has been compiled using information from a number of reliable sources, including:


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