PARENT'S GUIDE FACTSHEET

Children's Cancer and Leukaemia Group

# Rhabdomyosarcoma

Rhabdomyosarcoma is a type of soft tissue sarcoma (tumour). Fewer than 60 children are diagnosed with rhabdomyosarcoma in the UK each year. Most of them are younger than 10 years old. 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. 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'.

## Sarcomas

Sarcomas are rare types of tumour 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

Rhabdomyosarcoma is the most common of 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, bladder, testes, uterus, or vagina.

Sometimes tumours are also found in a limb, in the chest or in the abdominal wall. If the tumour is in the head or neck area, it can occasionally spread into the brain or the fluid around the spinal cord.

## Causes

The causes of rhadomyosarcoma are unknown but research is going on all the time. Children with certain rare genetic disorders, such as Li-Fraumeni syndrome, have a higher risk of developing rhabdomyosarcoma.

## Symptoms

The most common symptom is a lump or swelling. Other symptoms will depend on the part of the body that's affected by the rhabdomyosarcoma:

- A tumour in the head or neck area can sometimes cause a blockage (obstruction) and discharge

from the nose or throat. Occasionally, an eye may appear swollen and protruding.
- A tumour in the abdomen (tummy) can cause pain or discomfort in the abdomen and difficulty going to the toilet (constipation).
- A tumour in the bladder may cause symptoms such as blood in the urine and difficulty passing urine.

## How rhabdomyosarcoma is diagnosed

Different tests are usually needed to diagnose a rhabdomyosarcoma. Your child may need a small operation to remove a sample from the tumour (a biopsy) so that it can be examined under a microscope. This is usually done under a general anaesthetic.

Tests may be done to check the exact size of the tumour and to find out if 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.

## Staging

The 'stage' of a cancer is a term used to describe its size and whether it has spread from where it first started. Knowing the stage helps the doctors decide on the most effective treatment for your child. The staging system for rhabdomyosarcoma is based on:

- where in the body the tumour started
- if it is in only one part of the body (localised disease), or if it has spread to another part of the body (metastatic disease).

There are different ways of staging rhabdomyosarcoma, and your child's specialist doctor will explain more about the system they are using.

## Treatment

Rhabdomyosarcomas are rare tumours and should be treated at specialist centres. Treatment will depend on the size of the tumour, the type of rhabdomyosarcoma, its position in the body and whether it has spread. The three main types of treatment for soft tissue sarcomas are chemotherapy, surgery and radiotherapy. Your child may have a combination of treatments.

### Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It can be given:

- to shrink the tumour before surgery
- after surgery to reduce the risk of rhabdomyosarcoma coming back

The drugs used and the length of treatment depends on the type and stage of the rhabdomyosarcoma.

### Surgery

If it is possible, your child will have an operation to remove all or as much as possible of the tumour, without damaging surrounding tissue or organs. The operation will depend on the size of the tumour and where it is in your body. The surgeon will explain what is involved. Chemotherapy is usually given before surgery to shrink the tumour and make it easier to remove with surgery. If an operation isn't possible, both chemotherapy and radiotherapy are given.

### 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 may be given after surgery to the area where the rhabdomyosarcoma started.

## Side effects of treatment

The side effects will depend on the treatment being given and the part of the body that is being treated. Your child's doctor will discuss this with you before treatment starts. Most side effects are short-term (temporary) and gradually disappear once treatment stops.

Chemotherapy may cause side effects such as feeling sick, hair loss, tiredness, and an increased risk of infection. But it can also make your child feel better by relieving any symptoms the tumour is causing.

Radiotherapy can make your child feel tired, and the skin in the area that's being treated may go red or get darker. Other side effects will depend on the area of the body that is being treated. Your child's specialist doctor or nurse will explain this.

## Late side effects

A small number of children may develop long-term side effects many years after treatment for a rhabdomyosarcoma. This depends on the type of treatment your child had. Your child's doctor or nurse will talk to you about any possible risk of late side effects. Follow-up for children who've had cancer includes close monitoring for any signs of any late effects.

Late effects 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.

## 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 will be given plenty of time to decide if it's right for your child. There are many benefits of taking part in a trial.

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.

## 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

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 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.

## i 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.

**European Paediatric Soft Tissue Sarcoma Study Group (EpSSG)**
**www.epssgassociation.it**
International organisation for professionals involved with the care and treatment of children and young people with soft tissue sarcomas.

## References

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


- Pizzo P, et al. Principles and Practice of Paediatric Oncology. 7th edition. 2016. Lippincott Williams & Wilkins.
- Ocku M, et al. Rhabdomyosarcoma and undifferentiated sarcoma in childhood and adolescence: Treatment. www.uptodate.com (accessed April 2014).
- Childhood Rhabdomyosarcoma Treatment (PDQ®): Patient Version. PDQ Paediatric Treatment Editorial Board. PDQ Cancer Information Summaries [Internet]. Bethesda (MD): National Cancer Institute (US); 2002-2016 May 25.

Children's Cancer and Leukaemia Group

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.

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