



# Rare tumours in children

An information guide for parents, carers and families

The purpose of this guide is to give information about rare tumours 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.

## Types of rare cancers in children

Rare cancers in children make up fewer than 1 in 30 of all childhood cancers and can broadly be grouped as:

- rare cancers that only affect children, such as pancreatoblastoma, malignant rhabdoid tumours, pleuropulmonary blastomas and melanotic neuroectodermal tumours of infancy
- cancers that usually only affect adults, such as cancers of the digestive system, the thyroid and the adrenal gland
- rare cancers in the head and neck area, such as nasopharyngeal cancer
- rare hormonal/endocrine cancers, such as pheochromocytoma
- rare brain tumours, such as meningioma
- rare skin cancers, such as melanomas

## Causes of rare tumours

The causes of most rare childhood cancers are unknown. It is important to remember that nothing you have done has caused the cancer. If other family members have had particular types of cancer, this may sometimes suggest that there is an inherited gene in the family. If this is a possibility, your child's specialist will talk to you about it.

## Treatment

Rare cancers are treated with the same treatments used for other childhood cancers. This includes surgery, radiotherapy and chemotherapy. Your child may need a combination of these treatments.

Across Europe, there is now a body of experts in rare tumours for children who have a system to discuss difficult cases with standard guidance on how they should be treated. This is a big improvement in care over the last five years.

### Surgery

Usually, an operation is done to remove all or as much of the cancer as possible. Other treatments, such as radiotherapy or chemotherapy, may be given after or before surgery. They may also be used if an operation is not possible.

### Radiotherapy

Radiotherapy uses high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It can be used to treat any cancer cells that may be left behind after surgery, or to shrink a cancer.

## Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. It is usually given as injections and drips (infusions) into a vein. Chemotherapy may be used to lower the risk of the cancer coming back or to treat cancer that has spread to other parts of the body.

## Side effects of treatment

Treatment for rare tumours 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.

## Research and treatment guidelines

Clinical research trials may not be available for your child's particular tumour due to the small number of children with rare cancers.

Your child's doctor 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.

Doctors also communicate with specialist colleagues in other countries to promote research in rare tumours and develop new forms of treatment.

## Donating to a tissue bank

More research is needed to help doctors develop better treatment for rare childhood cancers in 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 rare tumours and how best to treat them. 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/life-after-childhood-cancer](http://www.cclg.org.uk/life-after-childhood-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. It is important to understand that not all side effects will happen to all patients.

## 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 reactions 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.





Children's  
Cancer and  
Leukaemia  
Group

the EXPERTS  
in CHILDHOOD  
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 information is accurate and up to date at the time of printing. CCLG does not accept responsibility for information provided by third parties, including those referred to or signposted to in the publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website. If you have any comments on this booklet, please contact us at [publications@cclg.org.uk](mailto:publications@cclg.org.uk).

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