Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Germ cell tumours in children

An information guide for parents, carers and families

The purpose of this guide is to give information about germ cell 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.

What are germ cell tumours?

Approximately 50 children in the UK develop malignant germ cell tumours each year. Most children who develop germ cell tumours will be cured.

Germ cell tumours can appear at any age. They develop from cells that produce eggs or sperm, so germ cell tumours can affect the ovaries or testes. However, it is also possible for a germ cell tumour to develop in other parts of the body.

As a baby develops during pregnancy, the cells which will later produce eggs or sperm normally move to the ovaries or testes. Sometimes, they can settle in other parts of the body where they can develop into tumours. The most common places for this to happen are the bottom of the spine, brain, chest, and abdomen.

Germ cell tumours are sometimes given different names based on what they look like under the microscope. These include **yolk-sac tumours**, **germinomas**, **embryonal carcinomas, mature teratomas** and **immature teratomas**.

They may be non-cancerous (benign) or cancerous (malignant). Malignant tumours have the ability to grow and spread to other parts of the body. Benign tumours do not spread but may cause problems by pressing on nearby tissue and organs. Immature teratomas fall between benign and malignant. These can occur at many different sites (most commonly in the abdomen) and can spread locally, but rarely outside their original area. They can usually be removed with an operation.

Causes of germ cell tumours

The exact causes of germ cell tumours are not known and research is ongoing. It is not infectious and cannot be passed on to another person. It is important to remember that nothing you have done has caused your child's cancer.

Signs and symptoms

The symptoms of germ cell tumours depend on where the tumour develops. Usually, it starts with a lump that can be felt or which causes other symptoms.

How it is diagnosed

A variety of tests and investigations may be needed to diagnose a germ cell tumour. Any tests and investigations that your child needs will be explained to you.

A small piece of the tumour will be removed and looked at under a microscope to find out if it is cancer or not. This is called a biopsy. It's a small operation, performed under a general anaesthetic. If the main tumour can be removed at the same time, this may happen as part of the same operation.

A CT or MRI scan may be used to check the exact position of the tumour and whether the cancer has spread to other parts of the body.

Germ cell tumours often produce proteins called tumour markers that can be measured in the blood. The ones that are produced by germ cell tumours are alpha-fetoprotein (AFP) and human chorionic gonadotrophin (HCG). Your child will have blood tests to check these tumour markers during diagnosis. The doctors will continue to check these during treatment and after treatment is over.

If your child has a germ cell tumour in the brain, these markers may also be detected in the fluid around the brain and spine called cerebrospinal fluid (CSF). This can be tested by doing a lumbar puncture.

Sometimes, a germ cell tumour can be diagnosed with tumour markers and scan results so that a biopsy isn't necessary. This happens if surgery is not needed for treatment or a biopsy may be particularly difficult. For example, if the tumour is in the brain.

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 to decide on the most appropriate treatment.

A general staging system is described below:

- **Stage 1** - the tumour is small, has not spread and can be completely removed by surgery
- **Stage 2 and 3** - the tumour is larger and may not be completely removed with surgery, or may have spread to nearby organs
- **Stage 4** - the tumour has spread to other distant parts of the body

Treatment

Germ cell tumours outside the brain

The treatment your child will have usually depends on a number of factors, including the size, position and stage of the tumour. It usually includes either surgery or chemotherapy, or a combination of the two.

A benign tumour can be cured if it is removed by surgery. It may mean removing a testicle or an ovary if this is where the tumour started.

If the tumour is malignant and can be completely removed with surgery, chemotherapy is not always needed, especially if it began in the testes or ovary. If the tumour cannot be removed easily or has spread, your child will be given chemotherapy.

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. Germ cell tumours are generally very sensitive to chemotherapy. It is usually given as injections and drips (infusions) into a vein. The combination of chemotherapy drugs and the length of treatment will depend on the position of the tumour, your child's age, the tumour marker levels and whether or not the tumour has spread.

Germ cell tumours within the brain

Treatment of malignant germ cell tumours in the brain is a little different. Although they are very sensitive to chemotherapy, treatment with radiotherapy is also needed.

Radiotherapy is the use of high-energy rays to destroy cancer cells. Germ cell tumours in the brain do not usually need to be removed with surgery. Depending on the type and stage of the tumour, radiotherapy is given either to part of the brain or the whole brain and the spine.

Side effects during treatment

Treatment for germ cell 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.

Clinical trials

Many children have their treatment as part of a clinical research trial. Clinical trials are carried out to try to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. 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. You will still receive the best standard treatment available.

National treatment guidelines

Sometimes, clinical trials are not available for your child's tumour. In these cases, your doctors 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.

Donating to a tissue bank

Germ cell tumours are rare 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 germ cell 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. 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.

Children who need treatment for germ cell tumours in the brain will need radiotherapy and this can cause long-term side effects, which your radiotherapy team will discuss with you in detail. These side effects will depend on how much radiotherapy is needed and will be checked for during follow-up

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

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.

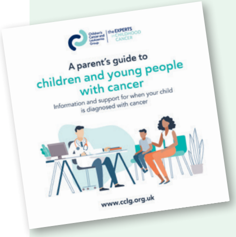
i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download.
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families

www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk



A parent's guide to
children and young people with cancer
Information and support for when your child is diagnosed with cancer

www.cclg.org.uk

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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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.

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