

Germ cell tumours - fact sheet



Germ cell tumours occur when abnormal germ cells grow in an uncontrolled way.

A germ cell is the type of cell that develops into eggs (in the ovaries) or sperm (in the testicles). Germ cell tumours can develop before or after birth, and can occur in the ovaries or testicles, or in other parts of the body. This is because sometimes, when babies are developing in the womb, germ cells travel to other parts of the body. Germ cell tumours can release hormones or enzymes that can cause signs and symptoms.

Germ cell tumours that form in the ovaries or testicles are called gonadal germ cell tumours. Those that form in the brain or spinal column are called intracranial or intraspinal germ cell tumours, and those that form in other parts of the body are called extracranial, extragonadal germ cell tumours. Germ cell tumours that are extracranial and extragonadal tend to form along the midline of the body, such as in the bottom of the spine, at the back of the belly, between the lungs or on the neck.

Germ cell tumours can be 1 of 3 types:

- **Mature teratomas** are benign tumours that are not likely to become cancerous. They usually occur in the bottom part of the spine in babies, or in the ovaries of girls when they reach puberty. These are the most common type of extracranial germ cell tumours.
- **Immature teratomas** might become cancerous. They usually occur in the bottom part of the spine in babies, or in the ovaries of girls when they reach puberty. They can contain several types of cells, such as bone, hair and muscle.
- **Malignant germ cell tumours** are cancerous. They are divided into germinomas and nongerminomas, depending on the type of hormone they release. Germinomas are the most common type of intracranial germ cell tumour.

Risk factors

A risk factor is anything that increases a person's chance of developing a certain condition or disease, such as cancer. In adults, lifestyle and environmental factors (such as smoking or exposure to certain chemicals) can be significant risk factors for developing certain types of cancer. In children, very few risk factors have been identified that increase the chance of developing cancer. For most children with cancer, the underlying cause is unknown.

Even if your child has a risk factor, it does not mean they will develop cancer. Many children with a risk factor will never develop cancer, while others with cancer may have had no known risk factors. Even if a child with a risk factor develops cancer, it is usually hard to know how much that risk factor contributed to the development of their disease.

The causes of germ cell tumours are not well understood, but factors associated with a higher chance of developing germ cell tumours include the following.





Genetic conditions

Genetic conditions that affect the sex chromosomes can increase the chance of your child developing a germ cell tumour. These include Klinefelter syndrome, Swyer syndrome and Turner syndrome.

If your child is diagnosed with one of these genetic conditions, they will need specific follow-up. The health care team will advise which ongoing tests your child will need.

Cancers in children that are linked to genetic conditions may also affect the risk for other family members. Speak to your child's treatment team to see whether genetic counselling is recommended for you or your family.

For more information about genetic conditions, see the [children's cancer glossary](#) or the [Centre for Genetics Education](#).

Other factors

Male children who have an undescended testicle may have a higher chance of developing testicular germ cell tumours.

Symptoms

Symptoms of germ cell tumours depend on where the tumour is, how big it is and whether it produces hormones. Symptoms of germ cell tumours outside the brain may include:

- a lump in the abdomen (belly), lower back or testicle
- abdominal (belly) pain
- fever
- constipation
- in girls, not having periods or having unusual bleeding from the vagina.

Germ cell tumours in the brain may cause symptoms such as:

- extreme thirst
- frequent urination
- headaches
- nausea or vomiting





- changes in vision
- loss of appetite
- weight loss
- tiredness
- early or late puberty.

Note about symptoms

Many conditions – including common childhood infections – can cause these symptoms, not just germ cell tumours. If your child has any of these symptoms and you are concerned, talk to your child's doctor.

Diagnosis

Your child will have a number of tests to investigate their symptoms and confirm a diagnosis of a germ cell tumour, including:

- medical history and physical examination, including a neurological examination
- eye examination
- blood tests
- medical imaging, which may include
 - X-ray
 - ultrasound
 - computed tomography (CT) scan
 - magnetic resonance imaging (MRI)
- biopsy – where a small sample of the tumour is removed to be examined under a microscope. The sample can also be tested for genetic changes that can help determine the best type of treatment for your child
- lumbar puncture (spinal tap) – where a sample of cerebrospinal fluid is taken to be examined under a microscope.

These tests are explained in more detail in [How is cancer diagnosed?](#)

Staging

If your child is diagnosed with a germ cell tumour, some of the diagnostic tests will also help to stage the tumour. Staging determines where the tumour is, how big it is and whether it has spread to other parts of the body. This is important to determine the outlook (prognosis) for your child, and to decide on





the best options for treatment.

There is no standard staging system for germ cell tumours in the brain. Instead, tumours are staged based on a range of factors that are classified into different risk groups.

For other types of germ cell tumours, there are different ways to assess the stage or extent of the cancer. Some of the most common ways are described below. For more information about staging, see the publications from the [National Cancer Institute](#).

Germ cell tumours that are not in the brain can be staged as follows:

- Stage I – the tumour is only in 1 place in the body and has been completely removed by surgery.
- Stage II – the cancer has spread to the outer covering of the organ, or to nearby lymph nodes. Surgery has removed all visible cancer, but some cancer cells remain.
- Stage III – surgery cannot remove all the visible cancer, or the cancer has spread to the lymph nodes.
- Stage IV – the cancer has spread to other parts of the body such as the lungs, liver, brain or bone.

Treatment

Treatment and care of children with cancer is usually provided by a team of health professionals called a multidisciplinary team. Members of this team are specialists in children's cancers – they understand the differences between children's cancer and adult cancer, and each team member brings different skills in managing care to meet the needs of both you and your child.

The team will be led by a childhood cancer specialist (paediatric oncologist). Other members of the team depend on the age of your child and their type of disease, and may change over time as your child's needs change. A list of team members who might make up the multidisciplinary team can be found in [The treatment team](#).

Treatment for germ cell tumours depends on the age of your child, the stage of the disease, the biological features of the cancer and other factors identified during diagnosis. Treatment will be tailored to your child's particular situation, and may involve one or more of the following (see [How is cancer treated](#) for more detail).

Surgery

Your child may have surgery to remove all or part of the tissue containing the tumour. This can include removing one or both testicles, or one ovary and one fallopian tube.





Chemotherapy

Chemotherapy uses anti-cancer medicines to destroy cancer cells. It is often given as a combination of medicines to try to prevent the cancer cells from becoming resistant to just one or two medicines.

Chemotherapy medicines are given together in courses, often over a few days. Once the body has recovered from the side effects, the next course is given. Most children receive multiple courses of chemotherapy.

Chemotherapy may be used before surgery (to shrink the tumour and make it easier to remove) or after surgery (to destroy any remaining cancer cells).

Radiation therapy

Radiation therapy (also called radiotherapy) uses high-energy X-rays or other types of radiation to destroy cancer cells or stop them from growing. Children with germ cell tumours in the brain may have radiation therapy.

Radiation therapy is not commonly used to treat germ cell tumours in the brain in children under 3 years of age because it can have long-term side effects on developing brains. Young children usually have chemotherapy instead, and may have radiation therapy once they are old enough. If radiation therapy is included in your child's treatment, special care will be taken to reduce the risks.

Stem cell transplant

Some children with germ cell tumours in the brain may be treated using a stem cell transplant (also known as a bone marrow transplant), in combination with high-dose chemotherapy.

Careful observation

For a few carefully selected patients, specific treatment may not be needed. If your child has a tumour that is not growing or spreading, they might be monitored closely but not given any treatment until they develop symptoms, or until their symptoms change .





Support

Diagnosis of cancer in a child is a very difficult time for the child, their family and their friends. You might feel overwhelmed, scared, anxious or angry. These are all normal feelings. It is very important to seek support from family, friends, health professionals or other services to help you, your child and your family cope with cancer.

Talk to your child's treatment team if you are having difficulties coping.

[Living with children's cancer](#) has information about physical, emotional and practical issues during and after diagnosis and treatment. There is also a page with helpful links on [where to find support](#).

The [Cancer Council](#) in your state or territory can give you general information about cancer, as well as information on resources and support groups in your local area. Call the Cancer Council Helpline from anywhere in Australia for the cost of a local call on **13 11 20**.

For additional specific information about childhood cancer, contact any of the major [children's hospitals and networks](#) in your state or territory.

Chance of cure

Many children with cancer are cured of the disease. Children's bodies have great capacity for healing. Also, huge improvements have been made in the treatment of childhood cancer in the past few decades. In the 1980s, around 65% of children diagnosed with cancer were alive more than 5 years after their diagnosis. Today, around 83% of children are successfully treated and become long-term survivors.

Long-term survival (also called the outlook or prognosis) and treatment options depend on a range of factors, including:

- age of your child at diagnosis
- extent or stage of the cancer
- appearance of the cancer cells under the microscope (the shape, function and structure of the cells)
- how the cancer responds to treatment
- cancer or tumour biology, which includes
 - the patterns of the cancer cells
 - how different the cancer cells are from normal cells
 - how fast the cancer cells are growing.

Talk to your child's doctor about your child's individual disease, treatment options and outlook.





Clinical trials

Researchers are trialling new ways to diagnose and treat different types of cancer. Your child may be invited to be part of a clinical trial to test new ways of treating germ cell tumours.

New treatments have to go through very strict regulation and approval processes before they can be used in a clinical trial. Your child's doctor will explain everything about the trial and give you detailed written information. You will need to give special permission for your child to be part of the trial.

Participating in a clinical trial may or may not directly benefit your child, but the results of clinical trials today will help children with cancer in the future.

See [Clinical trials and research](#) for more information, including whether there are any clinical trials your child can join.

More information

For more information about germ cell tumours, see the treatment PDQs® from the National Cancer Institute (United States):

- [Childhood extracranial germ cell tumors](#)
- [Childhood central nervous system germ cell tumors.](#)

