Neuroblastoma is a cancer of types of cell nerve tissue called neuroblasts. Neuroblasts are young nerve cells mostly found in:

- the adrenal glands (near the kidneys)
- the tissues around the spinal cord in the neck, chest, abdomen and pelvis.

Many neuroblastomas start in the adrenal glands.

Neuroblastoma is most common in infants and children under five years of age. It is rare in children over 10 years old and very rare in adults.

**Chance of a cure**

One of your biggest concerns on learning your child has cancer may be about their chance of being cured.

Due to major advances in treatment, many children treated for cancer now survive into adulthood. Children diagnosed with cancer between 2004 and 2012 have a 5-year survival rate of 85%. In the 1980s, the 5-year survival rate for all cancers was about 73%.[1]

Talk to your child’s doctor about your child’s diagnosis, treatments and long-term survival. Long-term survival is also called the outlook or prognosis. It depends on several things, including:

- age of your child at diagnosis
- extent or stage of the cancer
- how the cancer cells look under a 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.

To learn more about survival for neuroblastoma in children, visit Australian Cancer Childhood Statistics Online.

**References**

Clinical trials

It’s possible that your child may be able to be part of a clinical trial. Clinical trials are research investigations to test new treatments, interventions or tests, or as a way to prevent, detect, treat, or manage various diseases or medical conditions. The patients involved in clinical trials are volunteers.¹

With regard to cancer, researchers run clinical trials to test new ways to:

- treat cancer
- find and diagnose cancer
- manage cancer symptoms and treatment side effects.

If a trial is available, taking part in one will be entirely the family’s decision.

It’s important to note that new treatments are strictly regulated and must be approved 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. If you wish your child to be part of the trial, you will need to give permission.

Participating in a clinical trial may or may not directly benefit your child. But the results of clinical trials today help children with cancer in the future. If you’re interested in participating in a clinical trial, ask your child’s doctor if there are any suitable for your child.

You can find further information on our Clinical trials and research page.

References


Diagnosis

When your child is diagnosed with cancer, it can feel overwhelming. This phase involves finding out if your child has cancer, and determining the type of cancer they have. Children’s cancer can be difficult to diagnose, as many symptoms are similar to those caused by less serious conditions, or injuries. This means that your child may need several tests and medical appointments before you receive confirmation that your child has cancer.

If your doctor thinks your child has neuroblastoma, they may undergo the following tests:

- medical history and physical exam
- blood tests
- urine tests
- medical imaging, such as:
X-ray, ultrasound, computed tomography (CT) scan, magnetic resonance imaging (MRI), bone scan, metaiodobenzylguanidine (MIBG) scan, positron emission tomography (PET) scan.

- biopsy, perhaps with a test for genetic changes to help find the best way to treat your child.
- bone marrow aspiration and biopsy, done from two separate places in the body at the same time (bilateral). Your child may have more than one of these tests.

Our section, How is cancer diagnosed? explains these tests in more detail.

The tests can:

- diagnose neuroblastoma
- determine the tumour’s size and exact location
- show if it has spread to other parts of the body.

Staging

Doctors use staging to describe how much the cancer has grown. Some of the tests for neuroblastoma will also help to stage the tumour. Staging measures:

- where the tumour is
- how big the tumour is
- what nearby organs it affects
- if the cancer has spread to other parts of the body.

Your doctor will use this information to determine the best way to treat the disease. Staging will also give your doctor an idea of how well these treatments are likely to work (prognosis).

How doctors stage neuroblastoma varies. The following four stages are part of the International Neuroblastoma Staging System (INSS), which is used after surgery:

- **Stage 1** – the tumour is in one part of the body. Surgery removes all parts of the tumour that the doctors can see.
- **Stage 2A** – the tumour is in one part of the body. Doctors have not removed all parts of the tumour that they can see during surgery.
- **Stage 2B** – the tumour is in one part of the body. Doctors have removed all parts of the tumour that they can see during surgery. However, neuroblastoma cells occur in nearby lymph nodes.
- **Stage 3** - involves one of the following
  - Doctors have not completely removed the tumour by surgery. The cancer has spread to the other side of the body or to nearby lymph nodes.
  - The tumour is on one side of the body but has spread to lymph nodes on the other side of the body.
  - The tumour is in the middle of the body and doctors cannot completely remove it by
surgery. It has spread to tissues or lymph nodes on both sides of the body.

- **Stage 4** – the tumour has spread to other parts of the body, such as
don distant lymph nodes
don liver
don bones
don bone marrow
don the skin.

- **Stage 4S** (also called special neuroblastoma) – the child is less than one year old. The tumour is only in one part of the body, and doctors have removed all parts of the tumour that they can find during the surgery. However, the cancer has spread to
don the liver
don skin
don bone marrow.

Doctors may also use the INRGSS, which uses symptoms and medical imaging to determine the stage before any surgery.\(^2\)

Stage L1 – Locoregional tumour without image-defined risk factors

- the tumour is only in one part of the body and there are no organs close to it that are at risk of being damaged by the tumour

Stage L2 – Locoregional tumour with one or more image-defined risk factors

- the tumour is only in one part of the body but is pressing on or wrapping around organs nearby

Stage M – Distant metastatic disease (except Ms)

- the tumour has spread to other parts of the body (bones, bone marrow, distant lymph nodes, liver)

Stage Ms – Stage L1/2 tumour with metastatic disease confined to skin and/or liver and/or bone marrow

- this is a specific subtype of neuroblastoma where the tumour has spread only to the skin, liver and/or bone marrow (less than 10% involvement) in patients younger than 18 months of age.

**References**


Risk factors

A risk factor is anything that increases a person’s chance of getting a certain condition or disease. Researchers know about some risk factors that increase the chance of developing cancer. However, for most children with cancer, the cause is unknown.

What we do know is that if a child develops cancer, it’s not because of something they, or their parents did to cause it. No one is to blame if a child develops cancer.

Even if your child has a risk factor, it doesn’t mean they will develop cancer. Many children with a risk factor will never develop cancer. Most children with cancer have no known risk factors. Even if a child with a risk factor develops cancer, the risk factor may not have had much to do with it.

Researchers don’t completely understand what causes neuroblastoma. However, there are some things that are linked to a higher chance of getting neuroblastoma.

Family history

In rare cases, neuroblastoma runs in families. This affects around 1% to 2% of children with neuroblastoma. When this happens, the cancer usually grows at a younger age than in children with no family history of the disease. In these rare cases, the cancer often affects multiple parts of the body.

Genetic conditions

A few children have genetic or inherited risk factors that increase their chance of getting cancer during childhood. Research links neuroblastoma that runs in families with faulty ALK or PHOX2B genes.

Certain genetic conditions can increase a child's risk of getting neuroblastoma. These include:

- Hirschsprung disease
- congenital central hypoventilation syndrome
- neurofibromatosis type 1.

If your child has one of these genetic conditions, they will need specific care. Your health care team will talk to you about which ongoing tests your child will need.

Childhood cancers that have links to genetic conditions may also affect other family members’ risk. You can ask your child's treatment team if you or your family should get genetic counselling.

To learn more about genetic conditions, see the children's cancer glossary or the Centre for Genetics Education.
Support and more information

A diagnosis of cancer in a child is difficult for all involved. It’s normal for you and your family to feel overwhelmed, scared, anxious or angry.

If you or others around you are having trouble coping, make sure you speak to your child’s treatment team. They have helped and supported many other families who have been through what you’re currently going through. Sometimes just letting other people know how you’re feeling helps you feel less alone.

Most children’s hospitals will allocate a social worker to each family to provide support throughout treatment. If you need support, contact your hospital-based social worker to let them know how you’re feeling and to see what support can be made available to you and your family, including music therapists, play therapists or education support staff.

The following webpages and organisations also offer support and/or extra information for children with cancer and their families:

- **Living with children’s cancer** has information about physical, emotional and practical issues during and after diagnosis and treatment.
- **Organisations** that can provide support and information.
- **Redkite** is a national organisation that provides emotional support, financial assistance, information and resources to families who have a child with cancer. You can reach them through their support line **1800 733 548 (1800 REDKITE)**, which is open (9am-7pm AEST), email support@redkite.org.au or live chat on www.redkite.org.au
- **Canteen** provides a service called Canteen Connect, an online community for young people aged 12-25 dealing with their own or a close family member’s cancer, and **Parent Connect**, an online community with resources, information and peer support on parenting through cancer. Online counselling is available seven days a week, including evenings. Visit https://canteenconnect.org or call 1800 835 932.
- **Neuroblastoma Australia** supports families of children with neuroblastoma.
- The **Cancer Council** in your state or territory can give you:
  - general information about cancer
  - information on resources and support groups in your area.
  - You can call the Cancer Council Helpline from anywhere in Australia on **13 11 20**.
- Any of the major children’s hospitals and networks in your state or territory can provide information about childhood cancer.

For more information about childhood neuroblastoma, see:

- **Neuroblastoma**, from the American Cancer Society
- **Neuroblastoma treatment (PDQ®)**, from the National Cancer Institute (United States)
Symptoms

Many conditions can cause the symptoms below, not just cancer. If your child has any of these symptoms and you are worried, talk to your child’s doctor. The earlier cancer is found, the better.

Symptoms of neuroblastoma include:

- lump or swelling in the belly, neck or chest, or under the skin
- stomach pain, feeling full or not wanting to eat, usually with weight loss
- swelling in the arms or legs (if a tumour is pressing on blood vessels or lymph vessels)
- problems going to the toilet (if the cancer grows into the bladder or bowel)
- bulging eyes, or dark circles around the eyes
- jerky, uncontrolled eye movements
- bone pain
- other unexplained pain
- weakness or paralysis (if the cancer is pressing on the nerves or spinal cord)
- trouble breathing or swallowing.

In some cases, neuroblastoma produces certain hormones that can cause:

- diarrhoea
- high blood pressure
- rapid heartbeat
- sweating
- flushing (blushing) of skin.

Most symptoms of neuroblastoma are caused when the cancer:

- grows into, or presses on, nearby tissues or organs
- spreads to parts of the body such as bones or bone marrow.

Treatment

Treatment for neuroblastoma depends on:
- the age of your child
- the stage of the cancer
- other factors
- risk stratification

Doctors will suggest treatments based on your child’s situation. Treatment may involve one or more of the following:

- surgery
- chemotherapy
- radiation therapy
- targeted therapy
- stem cell transplant
- other treatments.

Your team of doctors, called a multidisciplinary team (MDT), will care for and treat your child, and will ensure that all your child’s needs are considered while they have cancer treatment. The section called The treatment team has further information about this.

**Surgery**

Your child is likely to have surgery to remove all or part of the tumour. The extent of surgery required depends on the risk stratification of the disease. This may a complicated process that takes into account numerous clinical, pathological and radiological variables.\(^1\) Very low and low risk tumours may be treatable with surgery alone. Sometimes they require no treatment at all and are merely observed. Intermediate risk tumours are may be treated with surgery or chemotherapy or a combination of both. High risk tumours are treated with a combination of chemotherapy, surgery, radiotherapy, stem-cell transplantation, and targeted therapy.

**References**