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# When Your Child Has Neuroblastoma

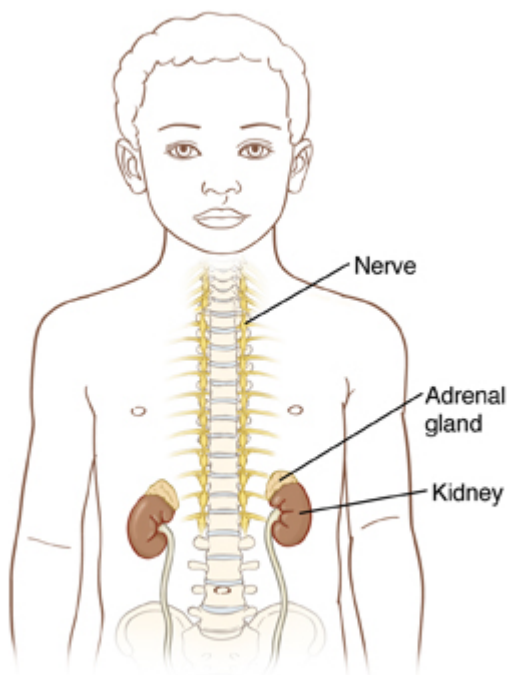
## What is neuroblastoma?

Neuroblastoma is a rare type of childhood cancer. It's the most common cancer in infants, but it's still very rare.

It starts in immature nerve cells outside the brain. Most of the time, this cancer starts in the adrenal glands. These glands sit on top of the kidneys. It can also start in nerve tissue near the spine in the belly (abdomen), chest, neck, or pelvis.

As the cancer cells grow and divide, they form a tumor. They can also spread (metastasize) to other parts of the body. Neuroblastoma may spread to the lungs, liver, bones, bone marrow, or lymph nodes. It can also spread to the area behind the eyes. In infants, it can spread under the skin.

Children of any age can get neuroblastoma. But it's almost always found in children ages 5 and younger. Sometimes this tumor can be seen on ultrasound before a baby is born. Different kinds of treatment can help shrink the tumor and make your child feel better. Your child's health care team will work closely with you to make decisions about your child's treatment.



## What causes neuroblastoma?

Neuroblastoma occurs when the genes in a cell are changed or damaged (mutated). This allows the cell to grow and divide out of control. Experts don't know what causes this. These gene mutations are random. And there's no known way to prevent them.

In a very small number of cases, the child has a family history of the tumor.

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# What are the symptoms of neuroblastoma?

The most common symptoms of neuroblastoma are caused when the tumor presses on nearby tissues or spreads to the bone. So symptoms depend on where the tumor starts.

Some of the more common symptoms are:

- A swollen stomach.
- Dark circles around the eyes.
- Bone pain.
- Bulging eyes.
- A lump in the belly, neck, or chest.
- Trouble breathing.
- Constipation.
- Trouble peeing.
- Painless, blue, or purple lumps under the skin.
- Weakness or not moving part of the body.

Less common symptoms include:

- A fever.
- A drooping eyelid with a small pupil.
- A fast heartbeat.
- Easy bleeding or bruising.
- High blood pressure.
- Severe, watery diarrhea.
- Uncontrolled eye movements and jerky muscle twitching. (This is also called “dancing eyes–dancing feet.”)

Many of these may be caused by other health problems. Always have a health care provider check your child if you notice these symptoms. Only a health care provider can tell if your child has cancer.

## How is neuroblastoma diagnosed?

Your child’s health care provider will do a physical exam and a neurological exam. You’ll be asked about your child’s past health and symptoms. Your child may also need tests, such as:

- **Blood or urine tests.** These are done to look for certain chemicals in the blood and urine. They can also show how well certain organs are working.

- **Imaging tests.** These are done to take detailed pictures of the inside of your child's body. These may include X-ray, MRI, CT scan, PET scan, or ultrasound. They help find where the tumor is, how big it is, and if the cancer has spread.
- **Biopsy.** This is done to take out tiny pieces of the tumor. These samples are then tested in a lab to look for cancer and learn more about the tumor.
- **Bone marrow aspiration and biopsy.** To do this test, small pieces of bone and bone marrow are taken from the back of the hip bones. They're tested to see if the cancer has spread to the bone marrow.

## Staging and grading of neuroblastoma

**Staging** is the process to note the size of the cancer and how much it has spread. Most cancers have their own staging system. These tumors are staged with the International Neuroblastoma Staging System on a scale of 1 to 4.

- **Stage 1** is early cancer. It's small and has not spread. For neuroblastoma, stage 1 means the tumor is in one place and can be fully seen and removed by surgery.
- **Stages 2 and 3** are more complex. The tumor is harder to remove, and cancer cells may have spread to nearby lymph nodes.
- **Stage 4** means cancer cells from the tumor have spread to other parts of the body, like distant lymph nodes, bone, bone marrow, the liver, lungs, skin, or other organs.

**Grading** is used to describe how abnormal the cancer cells look compared to healthy cells. The more abnormal the cells are, the faster they grow.

Staging and grading help the care team plan treatment for your child.

The care team also looks at:

- Where the main tumor is.
- Gene changes found in the cancer cells.
- Your child's age.
- How much of the tumor can be removed with surgery.
- Possible treatment side effects.
- Your child's overall health.
- Your choices and preferences.

Your child's care team will tell you more about the stage and grade of your child's cancer and what this means. Ask the health care provider if you have any questions about the details of your child's cancer.

## How is neuroblastoma treated?

Your child will be treated by many kinds of health care providers who specialize in caring for children with cancer. For instance, you and your child may see:

- A pediatric surgeon or neurosurgeon.

- A pediatric cancer specialist (oncologist).
- An endocrinologist.
- A neurologist.
- A neuroradiologist.
- A pediatrician.
- A social worker, counselor, child life specialist, or psychologist.

The goal of treatment is to remove or destroy cancer cells. The kind of treatment your child gets depends on the type and stage of tumor your child has.

These treatments may be used for neuroblastoma:

- **Watchful waiting.** Infants younger than age 6 months may not need treatment if they have small tumors and don't have symptoms. Sometimes these tumors go away on their own. If the tumors start to grow, treatment can be started.
- **Surgery.** This is done to remove all or part of a tumor. It might be the only treatment needed or, more often, it's done along with other treatments.
- **Chemotherapy (chemo).** This is the use of strong medicines to kill cancer cells. Most children with neuroblastomas get chemo. More than one chemo medicine may be used. Chemo is given through an I.V. (intravenous) tube that's put into a vein in the arm or chest. It might be used before or after surgery or as the main treatment.
- **Radiation therapy.** This uses high-energy X-rays to destroy cancer cells and shrink a tumor. It's not commonly used, but it may be part of stem cell transplant.
- **Stem cell transplant.** This treatment allows the care team to use high doses of chemo to kill the cancer cells. These doses also kill the healthy stem cells in the bone marrow, where blood cells are made. The transplanted stem cells are needed to rebuild the bone marrow after chemo. This is a serious procedure. It may be a choice for advanced stage neuroblastomas, fast-growing ones, or both.
- **Retinoid therapy.** These medicines are related to vitamin A. They might be used after stem cell transplant to help keep the cancer from coming back.
- **Immunotherapy.** These medicines help your child's immune system find and kill cancer cells. They may be used along with retinoid therapy after transplant. They might also be used to treat children over age 1 who have cancer in their bones or bone marrow that stops responding to other treatments or comes back after treatment.

Most children with cancer are treated as part of a clinical trial. These are research studies looking for new and better cancer treatments. They allow children to get the standard treatment used today, as well as new treatments that may work even better.

## Supportive care

During cancer treatment, your child will also get supportive care. The goal of this is to:

- Ease symptoms and side effects of the cancer and cancer treatment.
- Protect your child from infection.

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- Prevent discomfort and pain.
  - Keep blood counts in a healthy range.

Your child may be given:

- **Antibiotics** to help prevent and fight infection.
- **Antinausea and other medicines** as needed to ease side effects caused by treatment.
- **Blood transfusions** to restore the blood cells that have been destroyed by treatment. Blood is taken from a donor and stored until it's needed.

## Long-term care

Treatment for neuroblastoma can be hard on your child's body. Physical therapy may be needed to get the body working normally after treatment. Chemotherapy and radiation may also cause some long-term problems. These may include damage to certain organs, growth delays, learning difficulties, fertility problems, and hearing loss. Your child may be at a higher risk for another cancer later.

Your child's health will need to be watched from now on. Long-term follow-up may include clinic visits, hearing tests, blood tests, imaging tests, and heart ultrasounds.

## Getting support

Having a child with cancer can be scary and confusing. Remember that you are not alone. Your child's health care team will work with you during your child's illness and care. You may also want to get other kinds of support. This can help you cope with the changes that cancer can bring to your family. Contact these organizations for information and resources:

- [Children's Neuroblastoma Cancer Foundation at www.cncfhope.org](http://www.cncfhope.org)
- [Children's Oncology Group at www.childrensoncologygroup.org](http://www.childrensoncologygroup.org)