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**EASY READING**

# If Your Child Has Neuroblastoma

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## What is neuroblastoma?

Cancer is a disease where cells somewhere in the body start growing out of control. [Neuroblastoma](#)<sup>1</sup> is a type of cancer that starts in nerve cells that are not yet fully formed.

**Nerve cells** make up the nervous system, which includes the brain, spinal cord, and nerves. Some nerve cells give off chemicals that are sent to parts of the body and help us think, feel, touch, smell, hear, see, and move.

Most neuroblastomas start in the **sympathetic nervous system**. This is a part of the nervous system that helps control blood pressure, heart rate, and digesting food. Neuroblastoma tumors can start to grow anywhere these nerve cells are found, such as near the spine or in the belly, chest, or neck.

Some neuroblastomas grow slowly (and some might even shrink or go away on their own), while others can grow quickly and spread to other parts of the body.

Neuroblastoma happens most often in babies and young children. It is rare in children who are more than 10 years old.

## Questions to ask the doctor

- Why do you think my child has neuroblastoma?
- Is there a chance my child doesn't have neuroblastoma?
- What will happen next?

## How does the doctor know my child has neuroblastoma?

Neuroblastomas are often found when a child is brought to the doctor because of certain [signs or symptoms](#)<sup>2</sup>. (Some neuroblastomas are first seen on an ultrasound done during pregnancy, even before a child is born.)

If signs or symptoms are pointing to neuroblastoma, [tests](#)<sup>3</sup> will be done. Here are some of the tests your child may need:

### Blood and urine tests

Chemicals that may show neuroblastoma can be found in certain blood and urine tests. Other tests may also be done to check how the liver, kidneys, and other organs are working.

### Imaging tests

- **Ultrasound (sonogram):** An ultrasound may be one of the first tests done if the doctor thinks a child has a neuroblastoma. An ultrasound can be used to look for problems in the abdomen, but it can't be used to look at the chest or neck.
- **Chest or other x-ray:** An x-ray may be one of the first imaging tests done if a child has symptoms, although it can't always show a tumor.
- **MRI:** An MRI can show more details about some parts of the body. It is helpful for seeing the extent of a tumor. This test does not use radiation.
- **CT scan:** CT scans (sometimes called CAT scans) use x-rays to make detailed pictures of the inside of the body. This test can help tell if the neuroblastoma has spread outside of the nervous system.
- **MIBG scan:** A MIBG scan is usually done after a CT or MRI to see how far a neuroblastoma has spread. This scan uses a dye that attaches to neuroblastoma cells, and a special camera to take pictures of where the dye is in the body.
- **Bone scan:** A bone scan uses a different dye to look at all the bones in the body. If a MIBG scan is done, this test might not be needed.

- **PET scan:** A PET scan uses a dye and a camera, too. The pictures a PET scan takes are not as detailed as a CT or MRI scan. But a PET scan can help find neuroblastoma cells almost anywhere in the body.

## Biopsies

- **Surgical biopsy:** For this test, the doctor removes a piece of the tumor. The sample is then sent to the lab and looked at for cancer cells. Other lab tests might be done if cancer cells are found.
- **Bone marrow aspiration and biopsy:** This test might be done to see if neuroblastoma has spread to the bone marrow (the soft, inner parts of some bones). A doctor uses thin, hollow needles to remove small amounts of bone marrow, usually from the hip bone. The samples are sent to a lab to check them for cancer cells.

## How serious is my child's neuroblastoma?

Children with neuroblastoma are divided into [risk groups](#)<sup>4</sup>, based on things like the child's age, how far the cancer has grown or spread, and if the cancer cells have certain gene changes. The risk group helps doctors decide which treatment options are best. Ask the doctor to explain which risk group your child might be in and what it means for their outlook and treatment.

## Questions to ask the doctor

- Which neuroblastoma risk group is my child in? What does this mean?
- Are there any other factors that might affect my child's outlook?
- Will we need to see other doctors?
- How much experience do you have treating neuroblastoma?
- Will my child need any other tests?
- Who will do these tests?
- Where will they be done?
- How and when will we get the results?
- Who will explain the results?
- Does the tumor need to be treated? If so, how soon do we need to start treatment?
- What will happen next?

## What kind of treatment will my child need?

The [treatment](#)<sup>5</sup> plan that's best for your child will depend on:

- The risk group of the neuroblastoma
- The chance that a type of treatment will help
- Your feelings about the treatment and the side effects that could come with it

### Surgery

[Surgery](#)<sup>6</sup> to remove the tumor may be the only treatment needed for small neuroblastomas. If neuroblastomas are large or if they have spread, other treatment will be given as well.

### Chemo

[Chemotherapy](#)<sup>7</sup> (chemo) is the use of drugs to kill cancer cells. Children in certain risk groups need chemo as part of their treatment. It's one of the main treatments for most neuroblastomas that have spread to other parts of the body. Sometimes chemo is given before surgery, and sometimes after surgery.

Doctors give chemo in cycles, with each cycle followed by a rest period. Children often get more than one chemo drug at different times.

### *Side effects of chemo*

Chemo can have side effects like:

- Hair loss
- Mouth sores
- Loss of appetite
- Diarrhea
- Nausea and vomiting
- Increased risk of infections (because of low white blood cell counts)
- Bruising and bleeding easily (from low platelet counts)
- Tiredness (caused by low red blood cell counts)

These problems tend to go away after treatment ends. There are ways to treat most chemo side effects, so be sure to talk to your child's cancer care team so they can help.

## **Immunotherapy**

[Immunotherapy](#)<sup>8</sup> drugs are newer treatments that help the immune system attack the cancer. Some are now being used to treat high-risk neuroblastomas. Many others are now being studied as well.

## **Retinoid therapy**

[Retinoids](#)<sup>9</sup> are chemicals that are like vitamin A. Sometimes a retinoid drug is given after other treatment for neuroblastoma. Talk to your child's doctor to know if this kind of treatment may help with your child's neuroblastoma.

## **Radiation treatments**

### ***External beam radiation***

[Radiation](#)<sup>10</sup> uses high-energy rays (like x-rays) to kill cancer cells. Most children with neuroblastoma don't need radiation, but some might, depending on their risk group. Ask your child's doctor if radiation will be part of the treatment and what to expect. **Side effects of external radiation**

If your child's doctor suggests radiation treatment, ask about what side effects might happen. Side effects depend on where the radiation is aimed. The most common side effects of radiation are:

- Skin changes in the area where the radiation is given
- Feeling very tired

These side effects tend to get better after treatment ends. Radiation can also cause long-term effects if it reaches the brain, heart, lungs, or other organs. Talk to your child's cancer care team about what to expect.

### ***MIBG radiotherapy***

MIBG therapy is a kind of radiation therapy. It uses a chemical with radiation attached to it, which is injected into the blood to treat neuroblastoma.

## Side effects of MIBG

There are usually no serious side effects to MIBG therapy. The most common side effects are:

- Nausea and vomiting
- Feeling tired
- Swollen cheeks

## High-dose chemo and stem cell transplant

For children at high risk of the neuroblastoma returning after treatment, one or two [stem cell transplants](#)<sup>11</sup> might be advised. In this treatment, a child is given high doses of chemo (higher than could normally be given because of the damage it does to the bone marrow, where new blood cells are made). The child then gets blood stem cells to help rebuild the bone marrow. Other treatments, such as radiation therapy, retinoid therapy, and immunotherapy might be given after the transplant.

This is a complex treatment that can have major side effects (mainly from the high doses of chemo), so it needs to be done in a center that has experience doing stem cell transplants.

## Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better. Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find a clinical trial that might be right for your child, it's up to you whether to take part. And you can always stop at any time.

If you would like to learn more about clinical trials that might be right for your child, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)<sup>12</sup> to learn more.

## What about other treatments I hear about?

When your child has neuroblastoma, you might hear about other ways to treat the cancer or its symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your child's doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

### Questions to ask the doctor

- What are our treatment choices?
- What do you recommend and why?
- What's the goal of this treatment? Do you think it could cure the neuroblastoma?
- Will my child need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could my child have from these treatments?
- What can we do about side effects?
- Is there a clinical trial that might be right for my child?
- What about special vitamins or diets that friends tell me about? How will we know if they are safe?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- Is there anything we can do to help the treatment work better?
- Should we think about a stem cell transplant?
- What's the next step?

### What will happen after treatment?

You'll be glad [when treatment is over](#)<sup>13</sup>. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, your child will see their cancer doctor. Be sure they go to all of these follow-up visits. Your child will have exams, blood tests, and maybe other tests to see if the cancer has come back.

These doctor visits may be very frequent at first. Then, the longer your child is cancer-free, the less often the visits are needed.

### Hyperlinks

1. [www.cancer.org/cancer/neuroblastoma/about/what-is-neuroblastoma.html](http://www.cancer.org/cancer/neuroblastoma/about/what-is-neuroblastoma.html)
2. [www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/signs-and-](http://www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/signs-and-)

- [symptoms.html](#)
3. [www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/how-diagnosed.html)
  4. [www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/risk-groups.html](http://www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/risk-groups.html)
  5. [www.cancer.org/cancer/neuroblastoma/treating.html](http://www.cancer.org/cancer/neuroblastoma/treating.html)
  6. [www.cancer.org/cancer/neuroblastoma/treating/surgery.html](http://www.cancer.org/cancer/neuroblastoma/treating/surgery.html)
  7. [www.cancer.org/cancer/neuroblastoma/treating/chemotherapy.html](http://www.cancer.org/cancer/neuroblastoma/treating/chemotherapy.html)
  8. [www.cancer.org/cancer/neuroblastoma/treating/immunotherapy.html](http://www.cancer.org/cancer/neuroblastoma/treating/immunotherapy.html)
  9. [www.cancer.org/cancer/neuroblastoma/treating/retinoid-therapy.html](http://www.cancer.org/cancer/neuroblastoma/treating/retinoid-therapy.html)
  10. [www.cancer.org/cancer/neuroblastoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/neuroblastoma/treating/radiation-therapy.html)
  11. [www.cancer.org/cancer/neuroblastoma/treating/high-dose-chemo-radiation.html](http://www.cancer.org/cancer/neuroblastoma/treating/high-dose-chemo-radiation.html)
  12. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
  13. [www.cancer.org/cancer/neuroblastoma/after-treatment/follow-up.html](http://www.cancer.org/cancer/neuroblastoma/after-treatment/follow-up.html)
  14. <http://www.cancer.org>

## Words to know

**Biopsy** (BY-op-see): Taking out a small piece of body tissue to see if there are cancer cells in it.

**Chemotherapy** (KEY-mo-THAIR-uh-pee) or chemo (KEY-mo): The use of drugs to kill cancer cells.

**Immune system:** The body system that fights infection.

**Immunotherapy** (IM-yuh-no-THAIR-uh-pee): Treatments that uses the body's immune system to fight cancer.

**Malignant** (muh-LIG-nunt): Having cancer in it.

**Metastasis** (muh-TAS-tuh-sis): The spread of cancer cells from where they started to other places in the body.

**Neurons:** Nerve cells, or the main cells that make up the nervous system.

**Pediatric oncologist** (pee-dee-AT-trick on-KAHL-uh-jist): A doctor who treats children

who have cancer.

**Radiation** (RAY-dee-AY-shun): A type of treatment that uses high-energy rays (like x-rays) to kill cancer cells.

**Retinoids** (ret-uh-noyds): Vitamin A and man-made medicines similar to vitamin A, some of which can be used to treat neuroblastoma.

### How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org) (<http://www.cancer.org>)<sup>14</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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