If Your Child Has Neuroblastoma

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What is neuroblastoma?

Cancer can start any place in the body. Neuroblastoma is a type of cancer that starts in early forms of nerve cells. Nerve cells make up the nervous system.

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

To understand neuroblastoma, it helps to know a little about the nervous system. The nervous system includes the brain, spinal cord, and nerves. The nerve cells in the nervous system help the body work the way it should. The nerve cells give off chemicals that are sent to parts of the body and help us think, feel, touch, smell, hear, see, and move.

One part of the nervous system also helps the heart, lungs, and stomach work the right way. This is called the sympathetic nervous system. It helps control blood pressure, heart beats, and digesting food.

Most neuroblastomas start in the sympathetic nervous system. They can be found
anywhere along this part of the nervous system, such as the belly, chest, and neck. Some neuroblastomas grow slowly and others can grow quickly and spread to other parts of the body.

**Questions to ask the doctor**

- Why do you think my child has neuroblastoma?
- Is there a chance my child doesn’t have neuroblastoma?
- Would you please write down the kind of neuroblastoma you think my child might have?
- What will happen next?

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

Neuroblastomas are usually found when a child goes to the doctor because of certain symptoms. If signs are pointing to neuroblastoma, tests 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 can’t be used to look at the chest or neck.
- **Chest or other x-ray:** X-rays may be the first imaging test done when a doctor thinks a child has neuroblastoma. A chest x-ray can help tell if organs in the chest have problems. Sometimes x-rays of other parts of the body are taken too.
- **Magnetic resonance imaging (MRI) scan:** An MRI can give more details about some parts of the body. It is helpful in looking at the brain and spinal cord.
- **CT (computed tomography) 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 is able to find neuroblastoma
cells, and a camera to take pictures of bones and other parts of the body.

- **Bone scan**: A bone scan uses a dye and looks at all the bones in the body.
  Sometimes a MIBG scan is used and a bone scan is not used.
- **Positive emission tomography (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 laboratory and looked at by special doctors.
- **Bone marrow aspiration and biopsy**: This test might be done to see if
  neuroblastoma has spread. 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 see if there are neuroblastoma cells in the bone marrow.

**How serious is my child’s neuroblastoma?**

Neuroblastoma is not staged like most other cancers. Neuroblastoma is staged by
looking at what a child’s [risk group]¹ may be. Ask the doctor to explain which risk group
your child might be in. The risk group helps the doctor decide which treatment options
are best.

**Questions to ask the doctor**

- Would you write down exactly what kind of neuroblastoma my child has?
- Are there any factors that might affect my child’s outlook?
- Will we need to see other doctors?
- How much experience do you have treating neuroblastoma?
- What tests will my child need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will we get the results?
What kind of treatment will my child need?

The treatment plan that’s best for your child will depend on:

- The type and risk group of 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 may be the only treatment needed for small neuroblastomas. If neuroblastomas are large or if they have spread, then other treatment will be given.

Chemo

Chemotherapy or chemo for short is the use of drugs to kill cancer cells. Certain risk groups of neuroblastoma receive chemo. Sometimes chemo is given before surgery, and sometimes after surgery.

Chemo is one of the main treatments for most neuroblastoma that has spread to other parts of the body. Children might get more than one chemo drug at different times.

Doctors give chemo in cycles, with each cycle followed by a rest period.

Side effects of chemo

Chemo can have many 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)

But these problems tend to go away after treatment ends. There are ways to treat most chemo side effects. Be sure to talk to your child’s cancer care team so they can help.

Immunotherapy

Immunotherapy drugs are newer treatments. Many are being studied for certain types of neuroblastoma. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatment doesn’t. They might come as pills that your child takes at home. These drugs have side effects different from chemo and they are often not as bad.

Retinoid therapy

Retinoids 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 the kind of neuroblastoma your child has.

Radiation treatments

External beam radiation therapy

Radiation 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. If it’s given, radiation can kill any neuroblastoma cells that may be hiding in certain parts of the body. Ask your child’s doctor if radiation will be part of the treatment and what to expect. Side effects of radiation

If your child’s doctor suggests radiation treatment, talk 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 is aimed at 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 that is injected with radiation attached to it 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

**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 one that’s studying the kind of cancer your child has, 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](#) to learn more.

**What about other treatments I hear about?**

When your child has cancer 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 treatment do you think is best for my child?
- 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?
- What are our treatment choices?
- What do you recommend and why?
- Should we think about a stem cell transplant?
- What are the chances of curing the neuroblastoma?
- What’s the next step?

What will happen after treatment?

You’ll be glad when treatment is over. 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 your 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.

At first, the doctor visits may be about once a month. Then, the longer your child is cancer-free, the less often the visits are needed.

Hyperlinks

Words to know

**Aspiration** (ASP-er-AY-shun): A thin, hollow needle removes small amounts of bone marrow, usually from the hip bone. The samples are sent to a lab.

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

**Chemotherapy** (KEY-mo-THAIR-uh-pee) or chemo (KEY-mo): is 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 use the body’s immune system to fight cancer.

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

**Metastasis** (muh-TAS-tuh-sis): Cancer cells that have spread 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-AH-trick on-KAHL-uh-jist): A doctor who treats children who have cancer.

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

**Retinoids** (ret-n-oyds): Vitamin A and man-made medicines similar to vitamin A.

**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). 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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