

## **[Neuroblastoma - Childhood - Follow-Up Care](#) [1]**

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 04/2016

**ON THIS PAGE:** You will read about your child's medical care after treatment is finished and why this follow-up care is important. To see other pages, use the menu.

Care for children diagnosed with cancer doesn't end when active treatment has finished. Your child's health care team will continue to check to make sure the cancer has not returned, manage any side effects, and monitor your child's overall health. This is called follow-up care. All children treated for cancer, including neuroblastoma, should have life-long follow-up care.

Your child's follow-up care may include regular physical examinations, medical tests, or both. Doctors want to keep track of your child's recovery in the months and years ahead. Follow-up treatment care children treated for neuroblastoma depends on the risk grouping:

- **Low-risk or intermediate-risk neuroblastoma.** The child is evaluated every 3 to 6 months until 24 months after treatment ends, depending on the treatment given, the patient's age, and other factors. Then, the child is evaluated at least once a year.
- **High-risk, advanced neuroblastoma.** Follow-up care is decided on an individual basis. Tests are performed every few months for 2 to 3 years after treatment ends to find out whether the disease has recurred or gotten worse.

### **Watching for recurrence**

One goal of follow-up care is to check for a recurrence. Cancer recurs because small areas of

cancer cells may remain undetected in the body. Over time, these cells may increase in number until they show up on test results or cause signs or symptoms.

During follow-up care, a doctor familiar with your child's medical history can give you personalized information about the risk of recurrence. Your doctor will also ask specific questions about your child's health. Some children may have blood tests or imaging tests as part of regular follow-up care. However, testing recommendations depend on several factors, including the type and stage of cancer originally diagnosed and the types of treatment given.

## **Managing long-term and late side effects of childhood cancer**

Sometimes, side effects may linger beyond the active treatment period. These are called long-term side effects. In addition, other side effects called late effects may develop months or even years afterwards. Late effects can occur almost anywhere in the body and include physical problems, such as heart and lung problems and second cancers, and emotional and cognitive (memory, thinking, and attention) problems, such as anxiety, depression, and learning difficulties.

Based on the type of treatment the child received, the doctor will determine what examinations and tests are needed to check for long-term side effects and the possibility of secondary cancers. Your child's doctor can recommend the necessary screening tests. Follow-up care should also address the child's quality of life, including any developmental or emotional concerns. Learn more about the [childhood cancer survivorship](#) [3].

Possible long-term side effects or late effects of neuroblastoma treatment include:

- **Cardiovascular problems.** If your child received doxorubicin during chemotherapy, he or she may be at risk for heart problems, including weakening of the heart muscle. The doctor may recommend imaging of the heart with echocardiograms (echo) or other tests, as well as electrocardiograms (ECG or EKG) and blood pressure monitoring. The risk of these problems is related to the total dose of doxorubicin, but is also increased if the child received radiation therapy to the chest.
- **Hearing problems.** If your child has taken cisplatin/carboplatin, hearing loss is a possible side effect. Hearing tests are recommended at the end of treatment, and then once a year if the test results indicate a hearing problem.
- **Kidney problems.** If your child has taken cisplatin or had a bone marrow/stem cell transplant, the doctor will monitor kidney function by doing specific blood and urine tests as a part of a yearly visit. More tests may be needed if test results indicate a problem.

- **Hormonal changes.** If your child received radiation therapy, his or her primary care doctor will monitor growth and development yearly and evaluate your child for delayed puberty at age 12 (girls) or 14 (boys) through hormone blood tests.
- **Other cancers.** Children diagnosed with neuroblastoma are at increased for developing other cancers. The doctor will monitor your child for subsequent cancers using blood tests and physical exams. More tests may be needed if the test results indicate a problem.

## Follow-up care after radiation therapy

Children who have had radiation therapy may be at risk for other cancers, including:

- **Breast cancer.** If your child received total body radiation therapy or radiation therapy to the chest, your child should learn how to do a breast self-examination once he or she reaches puberty and perform them monthly. Regular mammograms may begin in early adulthood, rather than waiting until later in life.
- **Skin cancer.** You should learn to inspect your child's skin and ask the doctor to inspect any unusual skin findings at each yearly physical examination.
- **Other cancers.** It is important for children with cancer to receive regular primary medical care. Talk with your child's doctor if you are concerned about any symptoms, especially if your child has ongoing pain or a lump in an area that received radiation therapy.

## Follow-up care after stem cell transplantation/bone marrow transplantation

Children who have had a bone marrow or stem cell transplantation may have late effects. Possible late effects include:

- Problems with the way the thyroid gland, kidneys, lungs, and heart work
- Problems with growth
- Problems handling infections
- Increased risk of other cancers

- Problems with fertility, which is the ability to have a child, and hormones
- Hearing loss

Because of these possible problems, it is very important for children treated with stem cell transplantation to have certain tests and immunizations once each year. These may include the following evaluations:

- Heart tests, such as an echocardiogram and EKG
- Lung tests, such as pulmonary function testing (PFT)
- Blood tests that check the function of the kidneys, liver, and thyroid
- Immunoglobulin levels, such as IgG
- Hearing tests, if needed
- Eye examination, if the child received radiation therapy to the head or total body radiation therapy
- Dental examination
- Blood tests to evaluate hormone levels, such as testosterone, estrogen, and growth hormones
- If needed, an examination by an endocrinologist, a doctor who specializes in problems with glands and hormones
- Gynecologic examination for girls
- Immunizations as directed by the health care team

## Recommendations for long-term follow-up care

The Children's Oncology Group (COG) has studied the physical and psychological effects that childhood cancer survivors face. Based on these studies, COG has created recommendations for long-term follow-up care for childhood, adolescent, and young adult cancer survivors that can be found on a separate website: [www-survivorshipguidelines.org](http://www-survivorshipguidelines.org) [4].

## Keeping a child's personal health record

You are encouraged to organize and keep a personal record of the child's medical information. The doctor will help you create this. That way, as the child enters adulthood, he or she has a clear, written history of the diagnosis, the treatment given, and the doctor's recommendations about the schedule for follow-up care. ASCO offers [forms to help create a treatment summary to keep track of the cancer treatment your child received and develop a survivorship care plan](#) [5] once treatment is completed.

Some children continue to see their oncologist, while others transition back to the general care of their family doctor or another health care professional. This decision depends on several factors, including the type and stage of cancer, side effects, health insurance rules, and your family's personal preferences. Talk with your health care team about your child's ongoing medical care and any concerns you have about his or her future health.

If a doctor who was not directly involved in your child's cancer care will lead the follow-up care, be sure to share the cancer treatment summary and survivorship care plan forms with him or her, as well as all future health care providers. Details about the specific cancer treatment given are very valuable to the health care professionals who will care for your child throughout his or her lifetime.

*The [next section in this guide is Survivorship](#) [6]. It describes how to cope with challenges in everyday life after a cancer diagnosis. Or, use the menu to choose another section to continue reading this guide.*

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### Links

[1] <http://www.cancer.net/cancer-types/neuroblastoma-childhood/follow-care>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/22>

[4] <http://www-survivorshipguidelines.org/>

[5] <http://www.cancer.net/node/25394>

[6] <http://www.cancer.net/node/34286>