



After Treatment

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- [What Happens After Treatment for Neuroblastoma?](#)
- [Keeping Good Medical Records for Neuroblastoma](#)
- [Emotional and Social Issues in Children With Neuroblastoma](#)

Cancer Concerns After Treatment

Neuroblastoma survivors are at risk for possible late effects of their cancer treatment. It's important to discuss what these possible effects might be with your child's medical team so you know what to watch for and report to the doctor.

- [Late and Long-Term Effects of Neuroblastoma and Its Treatment](#)

What Happens After Treatment for Neuroblastoma?

Many children with neuroblastoma have a good chance of long-term survival following treatment.

After treatment for neuroblastoma, the main concerns for most families are the short- and long-term effects of the tumor and its treatment, and concerns about the tumor coming back.

It is certainly normal to want to put the tumor and its treatment behind you and to get back to a life that doesn't revolve around cancer. But it's important to realize that follow-

up care is a central part of this process that offers your child the best chance for recovery and long-term survival.

Follow-up exams and tests

After treatment, the doctor will likely order follow-up tests, which may include lab tests and [imaging tests](#) (MIBG scans, PET scans, ultrasound, CT scans, and/or MRI scans) to see if there is any tumor remaining. The tests done will depend on the [risk group](#), the size and location of the tumor, and other factors.

Because there is a chance that the cancer might return after treatment, it is very important to keep all follow-up appointments and to report any new symptoms to your child's doctor right away. The health care team will discuss a follow-up schedule with you, including which tests should be done and how often. Doctor visits, lab tests, and imaging tests to look for signs of recurrence are done more often at first. If nothing abnormal is found, the time between tests can then be extended.

A benefit of follow-up care is that it gives you a chance to discuss any questions and concerns that arise during and after your child's recovery. For example, almost any cancer treatment can have side effects. Some might last for only a short time, but [others can last longer](#) or might not show up until months or even years later. It's important to report any new symptoms to the doctor right away so that the cause can be found and treated, if needed.

It is also important to keep health insurance coverage. Tests and doctor visits cost a lot, and even though no one wants to think of the cancer coming back, this could happen.

- [References](#)

[See all references for Neuroblastoma](#)

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Keeping Good Medical Records for Neuroblastoma

As much as you might want to put the experience behind you once treatment is done,

it's very important to keep good records of your child's medical care during this time. This can be very helpful for your child and his or her doctors later on as an adult. Gathering the details soon after treatment may be easier than trying to get them at some point in the future. There are certain pieces of information you should be sure your child's doctors have. These are:

- A copy of the pathology report(s) from any biopsies or surgeries
- If your child had surgery, a copy of the operative report(s)
- If your child stayed in the hospital, copies of the discharge summaries that doctors prepare when patients are sent home
- If your child received chemotherapy or other medicines for the cancer, a list of the drugs, drug doses, and when they were given
- If your child got radiation, a summary of the type and dose of radiation and when and where it was given
- [References](#)

[See all references for Neuroblastoma](#)

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Late and Long-Term Effects of Neuroblastoma and Its Treatment

Both neuroblastoma itself and its treatment can sometimes result in long-lasting effects.

In very rare instances and for unknown reasons, in some children with neuroblastoma the body's immune system attacks the child's normal nerve tissue. This can lead to problems such as learning disabilities, delays in muscle development, language problems, and behavioral problems. Children whose tumors arise in the neck or chest and who have problems with the eyes or with muscle twitches may need further treatment with corticosteroids or other hormones to help keep their immune system in check.

Because of major advances in treatment, most children treated for neuroblastoma are

now surviving into adulthood. Doctors have learned that the treatment can affect children's health later in life, so watching for health effects as they get older has become more of a concern in recent years.

Treating childhood cancer requires a very specialized approach, and so does the care and follow-up after treatment. The earlier any problems can be recognized, the more likely it is they can be treated effectively.

Neuroblastoma survivors are at risk, to some degree, for several possible late effects of their treatment. It's important to discuss what these possible effects might be with your child's medical team.

The risk of late effects depends on a number of factors, such as the specific cancer treatments the child received, doses of treatment, and age when getting the treatment. Late effects of treatment can include:

- Heart or lung problems (from certain chemotherapy drugs or radiation therapy)
- Slowed or decreased growth and development (especially after a stem cell transplant)
- Bone damage or thinning of bones (osteoporosis)
- Changes in sexual development and ability to have children (especially in girls)
- Changes in intellectual function with learning problems
- Development of [second cancers](#), such as leukemia, later in life. These are not common, but they can occur.

There may be other possible late complications from treatment as well. Your child's doctor should carefully review any possible problems with you before your child starts treatment.

Along with physical side effects, survivors of childhood cancer may have [emotional or psychological](#) issues. They also may have some problems with normal functioning and school work. These can often be addressed with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help children after cancer treatment.

Long-term follow-up guidelines

To help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the Children's Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what type of screening tests should be

done to look for problems, and how late effects can be treated.

It is very important to discuss possible long-term complications with your child's health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child's doctors about the COG survivor guidelines. You can also download them for free at the COG website: www-survivorshipguidelines.org. The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as "Health Links") on the site as well, but we urge you to review them with a doctor.

For more about some of the possible long-term effects of treatment, see our document [Children Diagnosed With Cancer: Late Effects of Cancer Treatment](#).

- [References](#)

[See all references for Neuroblastoma](#)

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