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After Neuroblastoma Treatment

Living as a Neuroblastoma Survivor

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

- [What Happens After Treatment for 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](#)
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What Happens After Treatment for Neuroblastoma?

During treatment for neuroblastoma, the main concerns for most families are the daily aspects of getting through treatment and beating the cancer. After treatment, the concerns tend to shift toward the long-term effects of neuroblastoma and its treatment, as well as worries about neuroblastoma coming back.

It's certainly normal to want to put neuroblastoma and its treatment behind you and to get back to a life that doesn't revolve around cancer. But getting the right follow-up care offers your child the best chance for recovery and long-term survival.

Follow-up exams and tests

After treatment, the doctor will probably order follow-up tests, which may include lab tests and [imaging tests](#)¹ (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 child's [risk group](#)², the size and location of the tumor, and other factors.

Because there is a chance that the cancer might return after treatment, it's very important to go to 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](#)³ 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.

Ask your child's doctor for a survivorship care plan

Talk with your child's doctor about developing a [survivorship care plan](#)⁴. This plan might include:

- A summary of the diagnosis, tests done, and treatment given
- A suggested schedule for follow-up exams and tests
- A schedule for other tests your child might need in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from neuroblastoma or its treatment
- A list of possible [late or long-term side effects](#) from your child's treatment, including what to watch for and when to contact the doctor
- Diet and physical activity suggestions

Keeping records of health insurance and your child's medical care

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. Eventually, your child will grow up, be on his or her own, and have new doctors. It's important for your child to be able to give the new doctors the details of their cancer diagnosis and treatment. Gathering the details soon after treatment may be easier than trying to get them at some point in the future.

Ask your cancer care team where and how to get this information. Learn more in [Keeping Copies of Important Medical Records](#)⁵.

It's also important to keep [health insurance](#)⁶ coverage. Tests and doctor visits can cost a lot, and even though no one wants to think of neuroblastoma coming back, this could happen.

Can we lower the risk of neuroblastoma progressing or coming back?

If your child has (or has had) neuroblastoma, you probably want to know if there are things you can do that might lower the risk of it growing or coming back, such as having them eat a certain type of diet or take nutritional supplements. Unfortunately, it's not yet clear if there are things you can do that will help.

As your child gets older, adopting healthy behaviors such as [not smoking](#)⁷, [eating well, getting regular physical activity](#)⁸, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of behaviors can have positive effects on your child's health that can extend beyond their risk of neuroblastoma or other cancers.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of neuroblastoma progressing or coming back. This doesn't mean that there are no supplements that can help, but it's important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they're allowed to claim they can do. If you're thinking about having your child take any type of nutritional supplement, talk to your child's health care team. They can help you decide which ones can be used safely while avoiding those that might be

harmful.

To learn more, see [Dietary Supplements: What Is Safe?](#)⁹

Emotional and social issues in children with neuroblastoma

When a child is diagnosed with cancer, it is a crisis for the whole family. Younger children might not remember much about their experience after treatment is completed, but getting through it and helping them cope can be a challenge. Older children might have difficulty being away from school, friends, and activities that they enjoy, in addition to dealing with treatment stresses. Most pediatric cancer centers have special support programs and services to help children with cancer during treatment and for many years after treatment ends.

Parents and other family members, especially siblings, can also be affected, both emotionally and in other ways. The family's situation should be evaluated by the treatment center as soon as possible. Some common family concerns include financial stresses, traveling to and staying near the cancer center, the need for family members to take time off from work, the possible loss of a job, and the need for home schooling. Social workers and other professionals at cancer centers can help families sort through these issues.

To learn more about helping children with neuroblastoma and their loved ones cope during and after treatment, see [Finding Help and Support When Your Child Has Cancer](#)¹⁰.

Hyperlinks

1. www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/how-diagnosed.html
2. www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/risk-groups.html
3. www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html
4. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
5. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
6. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html

7. www.cancer.org/healthy/stay-away-from-tobacco.html
8. www.cancer.org/healthy/eat-healthy-get-active.html
9. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine/dietary-supplements.html
10. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/during-treatment/help-and-support.html

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Late and Long-Term Effects of Neuroblastoma and Its Treatment

Neuroblastoma can cause long-lasting side effects. Most of the long-term side effects depend on what kind of treatment a child had, where the tumor was located, and how old the child was when treated. Children who received several kinds of treatment (surgery, radiation, chemotherapy, immunotherapy, etc.) are more likely to have serious long-term side effects.

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.

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

After treatment, the cancer care team will create a [Survivorship Care Plan](#)¹ describing the treatments given and what that tells you about your child's risk of late effects. The plan will also describe how the child should be monitored for these problems. Most children do not experience all the problems they might be at risk for, but if problems do come up, it's important to find them early, so they can be treated effectively.

Depending on the treatment and other factors, late effects after neuroblastoma treatment might include:

- Hearing loss
- Problems with bones and muscles, like scoliosis (curving of the spine)
- Thyroid problems
- Problems with growth and development
- Fertility problems
- Neurological (nervous system) problems
- Second cancers, including leukemia
- Emotional or psychological issues

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, which can lead to symptoms such as rapid eye movements, muscle spasms, and lack of coordination. This is called [opsoclonus myoclonus syndrome](#)². Sometimes this syndrome improves or goes away after the neuroblastoma is treated, but some children might have longer-term problems such as learning disabilities, delays in muscle development, language problems, and behavioral problems. These children may need further treatment with drugs that suppress the immune system, such as corticosteroids or intravenous immunoglobulin (IVIG).

To learn more about some of the possible long-term effects of treatment, see [Late Effects of Childhood Cancer Treatment](#)³.

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 are used to create a child's Survivorship Care Plan. They can also help you know what to watch for, what types of screening tests should be done to look for problems, and how late effects can be treated.

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.org⁴. The guidelines are written for health care professionals, but patient versions of some of the guidelines are available (as "Health Links") on the site as well.

Hyperlinks

1. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-

- [care-plans.html](#)
2. www.cancer.org/cancer/neuroblastoma/detection-diagnosis-staging/signs-and-symptoms.html
 3. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html
 4. <http://www.survivorshipguidelines.org/>

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