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After Brain and Spinal Cord Tumor Treatment in Children

Living as a Survivor

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

- [What Happens After Treatment for Children with Brain or Spinal Cord Tumors?](#)

What Happens After Treatment for Children with Brain or Spinal Cord Tumors?

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

It's 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 the tumor. 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 visits and tests

Once treatment is finished, the health care team will discuss a follow-up schedule with you. It's very important to go to all follow-up appointments.

In some cases, even with slow-growing tumors, some of the tumor may still remain after treatment. Even when childhood tumors are treated successfully, some might come back even many years later. (Your child's doctor should be able to give you an idea of how likely this is.)

[Imaging tests](#)¹ (CT or MRI scans), physical exams, and sometimes other tests will be done after treatment to help determine how successful it was. Whether the tumor was removed completely or not, your child's health care team will want to watch your child closely, especially in the first few months and years after treatment to watch for tumor growth or recurrence. Depending on the type and location of the tumor and the extent of the treatment, the team will let you know which tests need to be done and how often.

During this time, report any new symptoms to your child's doctor right away, so the cause can be determined and treated, if need be. Your child's doctor can give you an idea of what to look for. If your child needs further treatment at some point, the doctor will go over the options with you.

Some children might need follow-up tests for many years after treatment. For example, children who get radiation therapy to treat their brain tumors are at increased risk of getting another tumor, so imaging tests might be needed for many years later to look for them.

Ask for a survivorship care plan

Talk with your child's treatment team about developing a [survivorship care plan](#)² for them. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests they 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 their tumor or its treatment
- A list of possible late- or long-term side effects from treatment, including what to watch for and when you should contact the doctor
- Diet and physical activity suggestions

Recovering from the effects of the tumor and its treatment

The tumor and its treatment might cause physical, mental, and emotional side effects, which can range from very mild to fairly severe. A child's brain is often better able to adjust to changes than an adult's, but it's also more sensitive to treatments such as radiation. What's more, some effects might be long-lasting or might not show up until years after treatment.

Once your child has recovered from treatment, the doctors will try to determine the extent of any damage to the brain or other areas. In a very young child this may take time. Physical exams and imaging tests (CT or MRI scans) will be done to determine the extent and location of any changes in the brain.

Several types of doctors and other health professionals might help look for these changes and help your child recover.

- A **neurologist** (a doctor who specializes in medical treatment of the nervous system) may assess your child's physical coordination, muscle strength, and other aspects of nervous system function. A neurologist can also help manage seizures if your child has them.
- If there is muscle weakness or paralysis, your child will be seen by **physical and/or occupational therapists** and perhaps a **physiatrist** (a doctor who specializes in rehabilitation) while in the hospital and/or as an outpatient for physical therapy.
- If speech is affected, a **speech therapist (speech-language pathologist)** will help your child improve talking and communicating.
- If needed, an **ophthalmologist** (a doctor who specializes in eye problems) will check your child's vision, and an **audiologist** can check your child's hearing. If problems with vision or hearing are found, your child may need some type of special education.
- Your child may also be seen by a **psychiatrist** or **psychologist** to determine the extent of any damage caused by the tumor and by treatment. The doctor will document your child's development in areas such as general intelligence, speech and hearing, memory, and learning skills.
- If the tumor was in or near the base of the brain or if radiation therapy was given to this area, the pituitary gland could be damaged, which could affect hormone levels. Sometimes this can lead to symptoms even before treatment, as a result of the tumor itself. If there is reason to think the pituitary has been affected, your child may be seen by an **endocrinologist** (a doctor who specializes in hormone disorders). Hormone treatments may be prescribed to restore normal hormone levels. For example, growth hormone can be given to help restore normal growth.

Late and long-term effects of treatment

A major concern of both parents and doctors is the potential for lasting effects from treatment, as well as effects that don't show up until years later. Some of these, such as learning problems or delayed growth and development, were mentioned above. Others might include [effects on the reproductive system](#)³ as boys and girls get older, or an increased risk of other cancers later in life. While doctors do everything they can to limit the chance of these complications, sometimes they may be an unavoidable part of making sure the tumor is treated properly.

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 are treated.

It's 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 read them on the COG website at www-survivorshipguidelines.org⁴. The guidelines themselves are written for health professionals, so you might want to go over the information with the child's treatment team. Information based on some of the guidelines, written for families of children with cancer, is also available (as Health Links) on the site.

For more about some of the possible long-term effects of treatment, see [Late Effects of Childhood Cancer Treatment](#)⁵.

Social, emotional, and other issues

Children can develop social and emotional issues both during and after treatment. Factors such as the child's age when diagnosed and the extent of treatment can play a role here.

Brain and spinal cord tumors and their treatment can sometimes affect how a child does some everyday tasks, including certain school, work, or recreational activities. These effects are often greatest during the first year of treatment, but they can be long-lasting in some children. It's important that the treating center assess the family situation as soon as possible, so that any areas of concern can be addressed.

Some children and teens may have emotional or psychological issues that need to be

addressed during and after treatment. Depending on their age, they may also have some problems with normal functioning and school work. These can often be helped with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help after treatment.

Many experts recommend that school-age children and teens attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is going on.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about diseases such as brain tumors. Some treatment centers have a school re-entry program that can help in situations like this. In this program, a teacher (called a *school liaison*) working with the hospital can help pave the way for your child going (back) to school by talking with the teachers, explaining your child's health issues, and discussing any special education techniques that might be needed. The liaison can also talk to the students about the diagnosis, treatment, and changes the child might go through, as well as answer questions from teachers and classmates.

With support from family, friends, other survivors, mental health professionals, and others, many people who have survived their tumor can thrive in spite of the challenges they've had to face.

For more information on these and other topics, see [When Your Child Has Cancer](#)⁶.

Keeping health insurance and copies of medical records

Even after treatment, it's very important to keep [health insurance](#)⁷. Tests and doctor visits cost a lot, and even though no one wants to think about a tumor possibly coming back, this could happen.

At some point after treatment, your child will likely be seeing a new doctor who doesn't know about their medical history. It's important to keep copies of medical records to give the new doctor the details of their diagnosis and treatment. Learn more in [Keeping Copies of Important Medical Records](#)⁸.

Hyperlinks

1. www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html

2. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html
4. <http://www.survivorshipguidelines.org>
5. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html
6. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer.html
7. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html
8. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html

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