



# After a Brain or Spinal Cord Tumor Diagnosis in a Child



Brain and spinal cord tumors are masses of abnormal cells inside the brain or spine. They can make it hard for the nerves of the brain and spinal cord to work normally to control how the rest of the body functions. If you have been told your child has a brain or spinal cord tumor, they've probably already had scans and a biopsy (a test that takes some tissue to check for cancer). Other tests might have been done on the cancer cells to check for certain proteins and gene changes called biomarkers. Your child might also have other procedures to find out if the cancer has spread. These tests help your child's doctor know what type of brain or spinal cord tumor your child has, what stage it is, and what treatment might help.

## Common types of brain tumors in children

These tumors are named for the part of the brain or spinal cord where the tumor formed. Not all of them are cancer. Some tumors are benign, or not cancer. Others are mixed types. Common types of brain tumors in children are:

- Gliomas
- Medulloblastomas
- Neuroblastomas
- Schwannomas

## Treatment for brain tumors

Brain and spinal cord tumors can often be hard to treat. Your child's treatment will depend on what type of tumor they have, where it is, how big it is, and its grade (how quickly the tumor grows and spreads). Your child's treatment options will also depend on test results on the cancer cells, their health and age, and your family's personal preferences.

Surgery is the first treatment for most children with a brain or spinal cord tumor. The type of surgery used depends on the tumor type, where it is, and how big it is.

If the tumor is benign, surgery may be the only treatment needed. If other treatments are needed, they may include radiation, chemotherapy (chemo), targeted therapy, immunotherapy, and stem cell transplant.

Your child may need more than one type of treatment. Several treatments can be used to help prevent or ease symptoms of the tumor. Sometimes, these are given along with other treatments. Your child's doctor will help your family decide which treatments are best for your child.

## Be sure to ask:

- What type of tumor does my child have?
- Where is the tumor?
- How big is the tumor? How fast is it likely to grow?
- What treatment do you think is best for my child?
- What is the goal of treatment?
- Will treatment include surgery?
- Can all of the tumor be removed? If not, why?
- Will my child need other types of treatment, too?
- Do we need to shave my child's head?

## What to expect before and during treatment

Your child's cancer care team will explain the treatment plan to you. This team may include different doctors, nurses, and other health care workers, depending on the type of treatment your child needs. For example, if your child needs surgery, you will work with a surgeon to learn what to expect before, during, and after treatment. If your child needs other types of treatment, the cancer care team will explain how it is given, help your child get ready for it, keep track of how they're doing, and help with any side effects. Your child might also get blood tests, scans, or other tests at certain times to see how well treatment is working.

Not everyone going through treatment for a brain or spinal cord tumor will have the same side effects. For example, the side effects of surgery are different from the side effects of radiation, chemo, or targeted therapy. And children getting the same treatment might have different side effects.

## Be sure to ask:

- What side effects might my child have, and what can we do about them?
- How will we know if the treatment is working?
- How often will my child get treatment? How long will it last?
- Where will we go to get treatment?
- Will my child be able to keep doing their usual activities, like going to school?
- How might treatment affect my child's ability to learn, grow, and develop?
- How likely is it that treatment could affect my child's future ability to have children?
- Are there any clinical trials that might be right for my child?

## What to expect after treatment

After treatment, ask your child's cancer doctor for a treatment summary and follow-up plan. This is called a survivorship care plan. Your child's cancer doctor will work with your family or primary care doctor to help manage side effects from treatment and check your child's general health. Your child will have regular tests to check if the cancer has come back or if a new cancer has started in a different part of their body.

Your child might be faced with changes to their body after treatment. They might have scars if they've had surgery. They might also have hair loss. Some treatments may cause problems with how their brain works. Be sure to ask the doctor what to expect, and let them know if your child has any problems.

Children who have had a brain or spinal cord tumor are at risk of having it again or getting certain other types of cancer. Even if your child feels fine after treatment, it's important to ask the cancer care team about a regular schedule for follow-up tests. These tests check if the cancer has come back.

For some children, the cancer might not go away completely. They might continue to get treatment, and tests will still be needed to see how well it's working.

## Be sure to ask:

- Where do I get a copy of my child's treatment summary and follow-up plan?
- How often does my child need to see their cancer care team?
- When and how should we contact them?
- Will my child need tests to see if the tumor has come back, or to check for problems from treatment?
- Are there late or long-term side effects from treatment that we should watch for?
- Where can we find my child's medical records after treatment?



For more information and support, visit the American Cancer Society website at [cancer.org/childhoodbraintumors](https://cancer.org/childhoodbraintumors) or call us at **1-800-227-2345**. We're here when you need us.



## Staying healthy

Be sure to tell your child's cancer care team if any treatment side effects don't go away or if your child has any new symptoms.

There are things your child can do to keep themselves healthy during and after treatment. Eating healthy foods, staying active when possible, getting enough rest, and keeping up with follow-up doctor visits can help support their health.

Certain conditions that increase a child's risk for brain and spinal cord tumors can run in families. Sometimes, genetic testing is done to know if a person has a type that might be inherited. Talk to your child's cancer care team to find out if genetic testing is right for your family.

## Dealing with your feelings

Having a brain or spinal cord tumor might make your child feel scared, sad, or nervous. It's normal to have these feelings, and there are ways to help your child cope with them.

- Encourage your child to talk about their feelings, no matter what they are.
- It's OK for your child to feel sad or down once in a while, but let your child's cancer care team know if your child has these feelings for more than a few days.
- If your child's doctor says it's OK, let your child continue to do things they enjoy, like spending time outdoors or going to a movie or sporting event.
- Help your child with daily tasks like homework.

You and your child might want to reach out to friends, family, or religious leaders or groups. Counseling can also help. Some people find it helpful to talk with others who've been through the same things. A support group can offer that. Tell your child's cancer care team how your child is feeling. They can help your family find the right support.