

# Talking with your Children about a Brain Tumor Diagnosis

## *For young children*

- A brain tumor is a lump in the brain that doesn't belong there. The doctor is going to operate and take it out. The operation will help get rid of [the patient's] symptoms.
- With the tumor in there, the computer center of the brain doesn't work the way it's supposed to. That's why [the patient] gets headaches and seizures.
- No one knows what causes a brain tumor. They just happen. But we do know that nothing you did, or thought, or said, caused the tumor. Nothing you ever wished made this happen. Nothing your brother or sister or friends said made this happen.
- We also know that you don't "catch" brain tumors from other people. They just happen. You won't catch a brain tumor from [the patient].

## *For older children*

- A brain tumor is a collection of abnormal cells in the brain which are growing out of control. These cells were originally normal brain cells. For no good reason, they started to divide and make more of themselves. This growing collection of cells is called a tumor.
- As the cells continue to make more of themselves, the tumor gets bigger and bigger, like a balloon inflating. Since there isn't a lot of extra room in the brain, the tumor may start to squish areas of the brain, causing them not to work properly.
- The doctor does not have a prognosis yet — that's a prediction of what will happen to the [patient] because of the brain tumor.

***For teens,*** use your best judgment. Most teens will want and appreciate detailed, accurate information. You will want to explain:

- A brain tumor is an abnormal mass of tissue or cells growing in the brain.
- The tumor is benign, meaning it's not cancer, but it's still pressing on the brain or the tumor is malignant, which means that it is cancer.
- The pressure on the brain from the tumor can cause [the patient] to lose important brain functions. They've done an MRI and the general location of the tumor is [show teen brain anatomy and point out where the tumor may be]. The doctors aren't sure yet what changes that will cause.
- [The patient] is going to need brain surgery by a neurosurgeon to remove the tumor.
- We don't know the prognosis yet. After surgery we will know more.



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# Talking with your Children about Tests, Treatment and Side Effects

## For young children

- The doctor wants to do some tests to find out why [the patient] is having headaches.
- A neurosurgeon is a doctor who knows a lot about the brain.
- During surgery, the neurosurgeon will open [the patient's] head and try to remove the tumor. It won't hurt [the patient], but [he/she] will need to stay in the hospital for a while.
- An MRI scan takes pictures of your brain, but it can't see what you are thinking.
- Chemotherapy is also called "chemo." [The patient] will go to the hospital [every day, every week] to get medicine that will try to kill the bad cells in the brain tumor. (You can modify this statement if the patient is taking chemo via pills at home.) The chemo might make [the patient] tired, or feel like throwing up, or both. It also may cause [the patient] to lose [his/her] hair, but it will grow back.
- Radiation therapy is another way to kill the bad cells in the brain tumor. [The patient] will go to a machine that uses energy rays to try and kill the bad cells. The machine won't hurt [the patient] but [the patient's] hair might fall out near where the tumor is. [He/she] might also not feel like eating, or feel tired.
- [The patient] will have some side effects from treatment. Side effects are problems caused by the medicine and treatments. Our doctor told us that [the patient] might feel [describe what the doctor has told you].
- [The patient] may have a seizure. A seizure is when a person's body begins to shake all over, and it seems like they don't have control of their body. It happens all of a sudden, and can look scary, but it's not dangerous.
- Because these treatments are all connected to [the patient's] brain, it might cause some changes in [the patient]. You know how you use your brain to walk and talk and think? The tumor or the medicines might cause changes in [the patient's] brain. [He/she] may start to have trouble moving or talking. [His/her] personality may change, and [he/she] might not remember things as well. [Describe what the doctor has told you].

## For older children and teens:

- [The patient] will need surgery to remove the brain tumor. [The patient] will be in the hospital for a while afterwards to recover. It may be a tough recovery. [Describe what the doctor has told you]. After the surgery, we'll talk with the doctors to see if [the patient] needs further treatment to reduce the tumor.
- Chemotherapy is also called "chemo." It's a treatment that uses drugs to kill cancer tissue. (You can discuss here whether and how often the patient will need to go to the hospital for chemotherapy treatment, or if the patient will be taking the chemo in pill form at home). Chemotherapy causes some side effects that might be hard for [the patient]. [He/she] might lose hair, which will grow back, experience nausea and vomiting, get mouth sores, feel tired (fatigue), and could have a greater chance of getting infections. The doctor told me that [the patient] might experience [describe what the doctor has told you].
- Radiation therapy is a treatment that uses high-energy rays to kill cancer cells. This treatment is given by a machine or by materials put in or near the tumor. [The patient] might lose hair where [he/she] is being treated, and might have trouble eating. [He/she] might also feel tired.
- [The patient] is going to participate in a clinical trial. That means [he/she] will be part of a research study that uses volunteers to compare new treatments with the standard or usual treatments.
- [The patient] may start to feel and act much differently than usual. The tumor and the treatment both affect the brain, so they may affect the parts that affect [his/her] physical movement and thinking. That means [he/she] could have trouble walking, talking, and [his/her] personality may change. It could also affect memory. [Describe what the doctor has told you].



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