CHAPTER 22A

Children with Brain Tumors – Special Considerations in Diagnosis and Treatment

Children are not just miniature adults. Specialist treatment can make the difference between just surviving... and quality survival.

Paul Zeltzer 2003
IN THIS CHAPTER
CHILDREN WITH BRAIN TUMORS

FINDING INFORMATION ABOUT CHILDHOOD BRAIN TUMORS

COMMON QUESTIONS ABOUT BRAIN TUMORS
Why did my child get a brain tumor? What did I do wrong?
What do you tell others? What do you tell your child?
Should you look into controversial treatments?
What is the controversy about radiation dose & diagnostic CAT scans?
How do doctors calculate medication dosages for growing children?

REASONS TO CONSULT A PEDIATRIC NEUROSURGEON
Can the choice of neurosurgeon influence survival?
Is a second opinion or surgery needed?
Tumor staging. Why is it important?
What if the neurosurgeon cannot remove the entire tumor?
Can you operate more than once on the same tumor?
Pain control for children: a neglected problem

CLINICAL TRIALS
Should you permit your child to participate?
Will your child be a “guinea pig” in a clinical trial?
What if you do not want standard therapy in a clinical trial?

RADIATION THERAPY
Are there specialists for children’s radiation?
What are the issues of lowered radiation dosage on younger children?
Radiation therapy and your child’s brain function
Will radiation therapy affect your child’s brain function?

SPECIFIC LATE EFFECTS OF TREATMENT OR TUMOR
Radiation, chemotherapy, surgery
Endocrine (Hormonal), puberty
CHAPTER 22A
Children with Brain Tumor

Key search words

- brain injury  
- radiation  
- late effects  
- pituitary  
- clinical trial 

- development  
- chemotherapy  
- endocrine  
- diabetes insipidus 

- pediatric neurosurgeon  
- medication  
- hormone  
- thyroid
INTRODUCTION

Previous chapters provide information about diagnosis and treatment of specific tumors and guide you on how to be the most effective advocate for your child. These techniques are the same for a spouse or a parent. This chapter provides important information about the unique features of the tumors and their treatment in the child. It includes information and guidelines that many families have learned and used to attain the best possible outcome. Helpful pamphlet, book, equipment, and web-linked resources specifically for children, including hormonal after-effects are highlighted and referenced in Table 22A-4. Social and psychological effects of the tumor and its treatment are detailed in Chapter 22B.

Children are not miniature adults. Their bodies and brains are growing, changing and have different reactions to treatments than adults. A brain tumor in a child means that special precautions must be taken, from the dose of x-rays of a CAT scan, radiation therapy or medications, to the choice of a treatment center. As a blessing for their innocence, children with brain tumors usually respond better to our current therapies than do adults with the same tumor.

FINDING INFORMATION ABOUT CHILDHOOD BRAIN TUMORS

Cancer is the number one cause of death from disease in children, and brain tumors account for 25 percent of these deaths. However, cancer is no longer a death sentence. By the year 2020, one in every 1000 United States’ citizens will be a survivor of childhood cancer. In fact, more than 60 percent of children with cancer survive the disease. Most child brain tumors start and grow in the lower, rear part of the brain (called posterior fossa). They differ in type and location from those in adults. (See Figures 22A-1, 2-2, 2-3.) Tumor types are listed in the glossary and in the chapters on primary tumors.

Children who are cancer survivors, however, experience a range of short and long-term effects in their medical health, psychological, cognitive and neuropsychological functions, all of which impact re-entry to the family and classroom. Nowhere are these effects more dramatic than with

Many children will experience long-term effects: physical, psychological, cognitive & neuropsychological.

Bottom Line 60% of children with cancer will be long-term survivors.
children who have nervous system tumors, the most common of all childhood cancers. Thus you must be aggressive in seeking resources and information to make the best choices. This is how Carol deals with her doubts about being “aggressive.”

If you think there’s something wrong with your kid...there probably is...if you request a test or something be checked out, don’t fear being proved wrong. If the test comes out negative, you win, as then you know that is NOT the problem (yea. If it turns out positive then you can start treatment and your child should start feeling better.

Don’t worry about hurting a doc’s feelings or wounding their ego. This is about YOUR child and getting the right thing done to insure proper treatment, NOT about them. This is their job; sometimes we just have to show, push or shove them in the right direction though.

Get used to it...it will be like this for as long as you parent this child.

Carol, mom to Mandy. Norman, OK

There are many sources for additional information. Brain tumor foundations have been started by parents, like yourself, whose children were diagnosed with a brain tumor. They have priceless knowledge from direct experience including materials and support which can help you: access to state-of-the-art treatment centers (see Chapter 7); and locate important web sites, chat rooms, list-servers; and opportunities for support and advocacy (see Chapter 4 and Table 22A-4). Books devoted to children with brain tumors can be found on booklists or by searching “brain tumor” or the search words on the first page of this chapter on any of the online bookstore web sites, or by doing a “Google” search (see Chapter 4).

**Figure 22A-1** Common Brain Tumors in Children

*Bottom Line*

Treatment at a Center specializing in children’s cancer that uses the most advanced therapies & clinical trials will increase your child’s chances for survival and quality of life.
Lenore and Murray, grandparents to Sophie, who has a newly diagnosed thalamic tumor, told me of a web site called “Caring Bridge.” It guides you step-by-step through the process of making a personal web site for your child and family. It allows you to post the latest news, findings and progress of your child as well as to upload links and photos. It’s an efficient and less time-consuming way of keeping your support circle of family and friends informed, so you don’t devote your limited energies to repeating the same routine on the phone 20 times a day. As a physician I had no idea how important this could be (see Table 22A-4).

COMMON QUESTIONS ABOUT BRAIN TUMORS IN CHILDREN

WHY DID MY CHILD GET A BRAIN TUMOR?

You will hear from well-meaning friends, television news programs, and magazines that fast foods, too many diet soft drinks, cell phones, and marijuana are the causes (see Chapter 24: Heredity and Other Causes of Brain Tumors). Forget it! You did not do anything wrong. About 5 percent of people with brain tumors have an inherited tendency to get one. If by chance there is a gene(s) that the family inherited, you received it from someone else, and it is only one of 15,000 other genes you have passed on to your family. You are no more responsible for that than your children’s eye color or height.

WHY DO I FEEL ASHAMED OR GUILTY WHEN I KNOW I SHOULD NOT?

You teach your child not to stick his or her hand on a hot stove, to cross the street after looking both ways, and to wear seat belts in the car. These are your responsibilities to make them safe. Then below your radar screen, a tumor comes in... and your lives seem irreversibly changed.

It is normal to feel guilty, hopeless, and worried. Nevertheless, you will move forward through that and do whatever is necessary to help your child. As a children’s oncologist and brain tumor specialist, I have never met a parent who did not suffer from guilt. It happens and you cannot prevent it.

**Bottom Line**

I have never met a parent who did not suffer from guilt. You could not prevent this brain tumor!