

Synopsis

Childhood Brain & Spinal Cord Tumors, the most complete parent guide available, includes detailed and precise medical information about both benign and malignant brain and spinal cord tumors that strike children and adolescents. In addition, it offers day-to-day practical advice on how to cope with procedures, hospitalization, family and friends, school, social and financial issues, communication, feelings, and, if therapy is not successful, the difficult issues of death and bereavement. Woven among the medical details and the practical advice are the voices of parents and children who have lived with cancer and its treatments. As many parents have already found, advice from "veteran" parents can be a lifeline. Obtaining a basic understanding of topics such as medical terminology, how drugs work, common side effects of chemotherapy, and how to work more effectively with medical personnel can only improve the quality of life for the whole family suffering along with their child. Having parents describe their own emotional ups and downs, how they coped, and how they molded their family life around hospitalizations can be a tremendous comfort. Just knowing that there are other kids on chemotherapy who refuse to eat anything but tacos or who have frequent rages can make one feel less alone. Parents who read this book will encounter medical facts simply explained, advice to ease their daily life, and tools to be a strong advocate for their child. Includes extensive resources and a pull-out medical record-keeper.

Book Information

Series: Patient-Centered Guides

Paperback: 568 pages

Publisher: Patient Centered Guides; 1 edition (December 15, 2001)

Language: English

ISBN-10: 0596500092

ISBN-13: 978-0596500092

Product Dimensions: 7 x 1.2 x 9.2 inches

Shipping Weight: 1.8 pounds (View shipping rates and policies)

Average Customer Review: 4.7 out of 5 stars 8 customer reviews

Best Sellers Rank: #2,666,688 in Books (See Top 100 in Books) #36 in [Books > Health, Fitness & Dieting > Diseases & Physical Ailments > Spinal Cord Injuries](#) #64 in [Books > Health, Fitness & Dieting > Diseases & Physical Ailments > Cancer > Brain Cancer](#) #202 in [Books > Textbooks > Medicine & Health Sciences > Allied Health Services > Caregiving](#)

Customer Reviews

For parents, there are few childhood diagnoses more frightening than a brain tumor. This is exactly the book to have in that situation. The latest entry in the excellent "Patient-Centered Guides" series, it maintains a nice balance between providing solid clinical information and sharing stories of emotional support. Chapters cover basic information about central nervous system (CNS) anatomy and physiology, types of tumors, and common procedures and treatments. Also discussed are personal and family issues such as dealing with school absences, making sure that siblings are not overlooked, asking for and accepting help from friends and family members, dealing with the emotional and financial disruptions brought on by illness, and facing death. Each chapter is sprinkled with small vignettes, told in the first person by parents of children with CNS tumors and at times by the children themselves. Appendixes include books, organizations, and web sites to consult for further information, as well as normal blood values for many commonly done tests. The authors include nurses experienced in caring for children with such tumors and the mother of a pediatric patient. Highly recommended for all public and health-related libraries. Eris Weaver, Redwood Health Lib., Petaluma, CA Copyright 2002 Cahners Business Information, Inc.

Maria Sansalone has a Bachelor's in English from American International College, and an Associate's in Science degree. She has worked in the past in hospital settings in the area of health information management, and for the last ten years as a Cross Reference editor for Merriam-Webster, Inc., the dictionary and reference publishers. Her position allows her access to information from almost every field. But, nothing, she says, prepared her for her son's diagnosis of an optic glioma. "It was a completely shocking and shattering experience, and it's taken many years to find a balance. Listening to families relate their own experiences for this book was immensely influential. I think it helped to bring things back full circle." Patsy Cullen received her BSN in nursing from the University of California, her MS from the University of Kansas, and her pediatric nurse practitioner training from the University of Colorado. She has worked as a pediatric nurse practitioner in Pediatric Oncology for more than 20 years and is currently a member of the staff of Childhood Hematology-Oncology Associates and the Rocky Mountain Children's Cancer Center in Denver, Colorado. She has published extensively in the areas of general pediatric oncology, radiation oncology and neuro-oncology. She has been a member of the Children's Cancer Group for twenty years, has served on the Nursing Discipline committee as Vice-Chair and now chairs the clinical trials subcommittee. Additionally, Patsy is now a Principal Investigator in the Children's Oncology Group, administratively heading the program at Presbyterian-St. Luke's Medical Center and was recently elected to serve on the group's Nominating Committee. She has held nursing

appointments on many national pediatric CNS tumor trials and is currently on the CNS Tumor Steering Committee for the Children's Oncology Group. Tania Shiminski-Maher received her BSN and MS in pediatric primary care from Columbia University. She is a certified as a pediatric nurse practitioner, clinical neuroscience registered nurse, and pediatric oncology nurse. She has worked as a pediatric nurse practitioner in pediatric neurosurgery and pediatric neuro-oncology for the past fifteen years. She has published extensively in the area of pediatric brain tumors, hydrocephalus and multidisciplinary team communication. She has been a member of the nursing committee of the Children's Cancer Group for the past fifteen years and a member of the nursing steering committee for ten years. She holds academic appointments to the faculty of New York University School of Nursing and Hunter-Bellevue School of Nursing.

My daughter was only 3-months old when she was diagnosed with a rare brainstem and spinal cord tumor. The morning after receiving the devastating news, I went to the hospital's library to check for resources, though I expected none. On the contrary, they showed me about half a dozen books which were relevant to her condition, this one being by far the most helpful. I went on to buy my own copy and have referenced it numerous times over the past two years since diagnosis. It is extremely thorough, written for those without a medical/scientific background, and continues to be a proven help for every step in this journey. It is also my "go to" resource for new families whom I meet who are just beginning down this road. The Chapters are as follows: 1. Diagnosis 2. The Brain and Spinal Cord 3. Types of Tumors 4. Coping with Procedures 5. Your Child's Hospitalization 6. Family and Friends 7. Forming a Partnership with the Medical Team 8. Surgery 9. Clinical Trials 10. Venous Catheters 11. Radiation Therapy 12. Chemotherapy 13. Common Side Effects of Chemotherapy 14. Bone Marrow and Stem Cell Transplantation 15. Feelings, Communication, and Behavior 16. Siblings 17. Nutrition 18. Record Keeping and Finances 19. Sources of Support 20. School 21. End of Treatment 22. Relapse 23. Death and Bereavement 24. Toward the Future I highly recommend this book to anyone caring for a child with a brain tumor diagnosis.

When my 6 year old niece was diagnosed with brain cancer last year, my family was devastated. Her parents are both RNs, and so could more easily understand a lot of the terminology and treatments. I have absolutely no medical background, and I found this book to be very helpful. This book provided comprehensive explanations of various treatments, commonly used drugs, different types of brain and spinal cord tumors, etc. that were easy for a layperson to understand. I also really liked that there were many shared experiences from other families who had dealt with childhood

cancer, it made me feel like we weren't alone. There are new treatments that come out all the time, so obviously some of the information may be dated, but overall I thought this was an excellent guide for anyone caring for a child with brain cancer.

This book is very informative if your child has a brain or spinal cord tumor. It is broken into easy to read sections. The quotes from people who already lived through this were priceless. It helps put things in perspective for you. It gives you tips on how to deal with unusual circumstances. It has lots of resources for contacting other organizations on the web as well. Very helpful for me and my family.

This book is a fantastic resource! It really helped me understand what doctors have been saying, the pathology report, and what to expect in the future. It is very thorough, covering diagnosis, treatment, complications, and even how to help children emotionally. I would definitely recommend this to anyone whose child is diagnosed with a brain or spinal cord tumor.

When our 5 year old daughter was diagnosed with a Brainstem Glioma, the hospital and Child Cancer Foundation (in New Zealand) gave us books to read, if you wanted to wade through all the technical stuff, personally I couldn't cope with it all. Then when I was looking at sites on the internet, I read about this book. I had a look at it at , and thought about it for a few days, trying to weigh up if it would be relevant to NZ'ers. I finally took the plunge and got it. I am soooo relieved that I did. Suddenly I was able to read something and actually get some benefit from it. The inserts from the parents are wonderful - suddenly I don't feel so alone, and the advice is universal. It relates to anyone in any country going through this nightmare.

As a parent to a child who had a brain tumor, I feel that this book covers all the major topics. When our son was diagnosed back in '98, I searched for such a book but none existed. Our son has since passed away but we are thankful that this book is available - particularly for newly diagnosed families. We purchased copies for our public library and for The Jimmy Fund in memory of our three year-old son, Kevin Kirsch. Thank you for writing this much needed guide. It will be a resource for caregivers and medical professionals alike.

This book is loaded with information you NEED to know to help you understand the disease, what the doctors are talking about, sources of information, the problems that pop up along the way, as

well as tips to help make the child much more comfortable. This should be the first book you read on the subject.

Having a daughter die of a Brain Stem Glioma, this book would have helped tremendously.

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