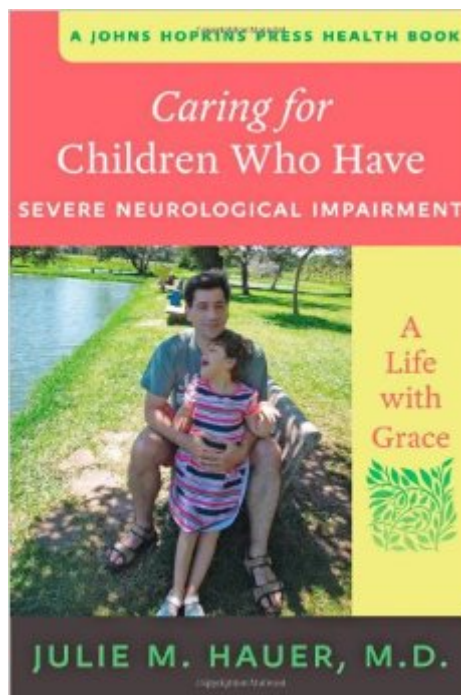


The book was found

Caring For Children Who Have Severe Neurological Impairment: A Life With Grace (A Johns Hopkins Press Health Book)



Synopsis

Global impairment of the central nervous system, whether stable or progressive, is often called severe neurological impairment (SNI). A child who has SNI will be cared for both by specialist clinicians and by parents at home. A parent is a child's best expert and advocate, and many parents become highly skilled in managing their child's care. This guide provides information to help parents increase their knowledge and improve their caregiving skills. In *Caring for Children Who Have Severe Neurological Impairment*, Dr. Julie M. Hauer advocates shared decision making between family caregivers and healthcare providers. She details aspects of medical care such as pain, sleep, feeding, and respiratory problems that will be particularly useful to parents. Tables and key points summarize discussions for clear, quick reference, while case studies and stories illustrate how different families approach decision making, communication, care plans, and informed consent. Parents and other caregivers will find this book to be indispensable—as will bioethicists and clinicians in pediatrics, neurology, physical and rehabilitative medicine, palliative care, and others who care for children with neurological and neuromuscular disorders. Dr. Hauer offers hope and practical coping strategies in equal measure.

Book Information

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Customer Reviews

If you are a parent with a child who has severe neuro issues, you know very well that our kids don't follow the usual rules. They are so complicated that it can be extremely challenging to get any help for them. This book FINALLY takes a look at caring for these kids, and provides tons of options for

the most common (and sometimes uncommon) problems they experience. It is also written in a tone of compassion and caring, clearly recognizing the value of these children's lives. If you have a kid with severe CP, HIE, or any other severe neuro disorder, this is the one book you will want to buy. While it is written for a somewhat medically sophisticated audience, I think most parents will still find the medical info easy to understand. In addition, every physician, nurse, and therapist who works with these kids should have a copy of this book in his/her possession. Most will find a lot of information in here that they likely have not seen before. I spent most of the past 10 years trying to sort all of this out for myself (as a parent), and to have it all collected in one book will be tremendously helpful to so many people. I wish I had it 10 years ago!

This book is written at a GP and specialist level but it quite comprehensible by most caregivers. From medication tables to basic neurology background, to strategies for pain management, decision making, medical team building, and more ... *Caring for Children With Severe Neurological Impairment* is the go to book. Finally a text written from the practical palliative care perspective - palliative care is not end of life care, it's optimizing quality of life. We strongly recommend this book for anyone caring for a loved one, of any age, with neurological impairment. We've suggest this for every MLD Family we care for ... and we use it when caring for our daughter with MLD. Dean Suhr, President, MLD Foundation p.s. Full disclaimer ... Dr. Hauer is a member of the MLD Foundation's Medical & Scientific Advisory Board. We've known her for years and she is a regular at our MLD Family Conferences(tm) not because she wrote a book, rather it's because she knows her stuff and has always been able to apply the science and complexity of medicine in a practical hands on way with families. Having her wrapped up in a book (paper or digital) is all the better! [...]

I have two sons with an unknown neurologic genetic condition (SNI) and this book has been so amazing it brings tears to my eyes just writing this review. My oldest has been in pain his whole life and although I suspected it, I never knew what to say to my physician who had no clue how to treat it. We tried one of the suggestions in her book and both my children have slept through the night for two weeks straight! The first time EVER! Dr. Hauer, THANK YOU for taking the time to write this book. It has empowered me with knowledge about my children so I have more than just my mom's intuition when I go to there many appointments. I wish there were more loving and kind doctors like you. For the potential reader, if your child has an unknown neurological issue, I highly recommend this book. It is very medical with lots of terminology including medication lists. I have to look some terms up online, but this is very important so you can speak your doctor's language. However it is

written for a caregiver, not a doctor. It talks about some sad topics like end of life but it is sadly all necessary when you have a complex child.

I am a parent of a young man age 19 with sensory, physical and profound learning disabilities and complex health care needs. His diagnosis is Lowe Syndrome; an ultra rare genetic metabolic disorder that is life limiting and life threatening. I really wish I'd had a book like this to help us when my son was younger; it will educate, encourage and reassure families on their incredible journeys with their incredible children with additional support needs. Although we live in the UK, the clear, methodical presentation of the processes and principles of ethical, family-based decision making in the book are worth reading about the world over. Highly, highly recommended. A book to savour, refer to, share and shout about.

This is a great read for parents or caregivers of children with special needs. This book provides readers with a better understanding of the complexity of an individual with special needs and how to help make them comfortable & help you understand different warning signs of medication withdrawal or toxicity. It also provides you with information on how to communicate with your child's care team due to this task being very difficult at times. It is a highly recommended read.

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