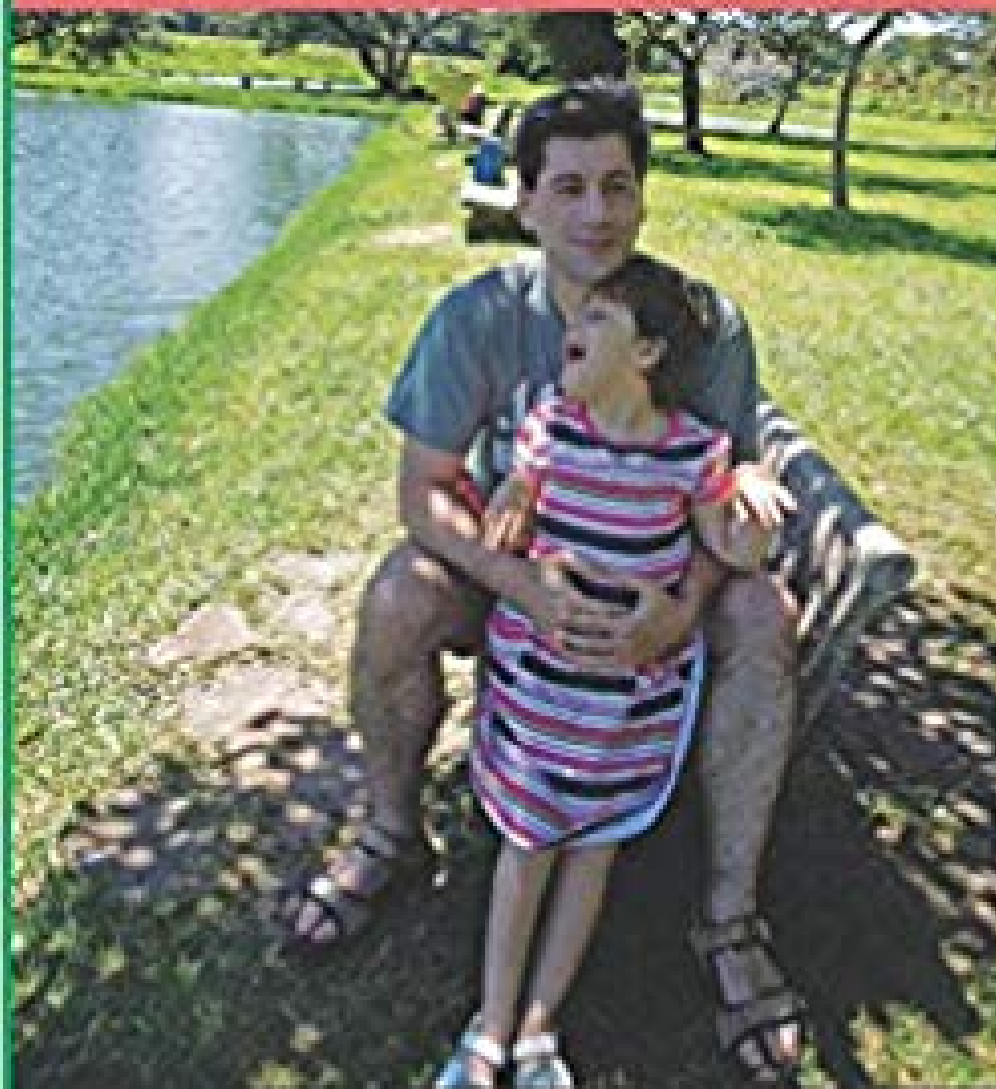


A JOHNS HOPKINS PRESS HEALTH BOOK

Caring for
Children Who Have
SEVERE NEUROLOGICAL IMPAIRMENT



A
Life
with
Grace



JULIE M. HAUER, M.D.

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Julie M. Hauer

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



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Global impairment of the central nervous system, whether stable or progressive, is categorised as serious neurological impairment (SNI). A kid who suffers SNI will be cared for both by professional clinicians and by parents in the home. A mother or father is a child's best expert and advocate, and many parents become very skilled in managing their child's care. This guide provides information to help parents boost their knowledge and enhance their caregiving skills. It details areas of medical treatment such as pain, sleep, feeding, and respiratory problems that will be particularly useful to parents. Hauer offers hope and useful coping strategies in equivalent measure. Hauer advocates shared decision making between family members, caregivers and healthcare providers. In *Caring for Children Who Have Severe Neurological Impairment*, Dr. Tables and tips summarize discussions for very clear, quick reference, while case research and tales illustrate how different families approach decision making, communication, care plans, and educated consent. Parents and other caregivers will find this book to be indispensable. Dr. as will bioethicists and clinicians in pediatrics, neurology, physical and rehabilitative medicine, palliative treatment, and others who look after kids with neurological and neuromuscular disorders. Julie M.



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The best go-to reference for caregivers of babies and children with severe brain disorders This book has been our go-to reference over the last few months, as we've coped with the different aspects of looking after our baby with epileptic encephalopathy and severe global developmental delay. Plus, it's written by an expert in the field. Hauer provides extensive information on the full gamut of conditions that come along with severe neurological disorders - not only seizures, but rather from feeding tubes to respiratory problems to urine problems to autonomic dysfunction. Most important can be her professional and compassionate validation that quality of life is essential - and she provides research-backed information that assists caregivers make informed decisions about treatments and interventions, confidently and security. Although the book is targeted towards specialists, as parents we've found it to be invaluable in helping us to better understand why our baby experiences certain challenges and the different valid options for intervening - or not really intervening - in each case. This book provide visitors with a better understanding of the complexity of an individual with unique needs and how exactly to help to make them comfortable & Will need to have for parents of children with complex neurological problems I have two sons with an unknown neurologic genetic condition (SNI) which book has been thus amazing it brings tears to my eyes just composing this review. My oldest has been around pain his whole life and although I suspected it, I never knew what to tell my physician who experienced no clue how to address it. We tried one of the suggestions in her book and both my children have slept during the night for two weeks straight! The 1st time EVER! Dr. Hauer, MANY THANKS for taking enough time to write this book. It provides empowered me with knowledge about my children therefore i have more than just my mom's intuition when I head to there many appointments. I wish there were even more loving and kind doctors like you. Scientific Advisory Board. Five Stars Excellent book for groups of children with neurological conditions, have recommended to many other parents Very Helpfull! However it is created for a caregiver, not a doctor. I must look some terms up online, but that is very important so you can speak your doctor's vocabulary. It talks about some unfortunate topics like end of life but it is unfortunately all necessary if you have a complex child. The ultimate caregiver's guide for those with neurological issues This book is written at a GP and specialist level but it quite comprehensible by most caregivers.Finally a text written from the practical palliative care perspective - palliate care is not end of life care, it's optimizing quality of life... Dr. From medication tables to fundamental neurology backgrounder, to strategies for pain administration, decision producing, medical team development, and more . I really like the case studies and may find advice/input on just about every issue that has come up for my newly human brain injured daughter. We've suggest this for each MLD Family we care for ... and we use it when caring for our daughter with MLD.Dean Suhr, President, MLD Foundationp.s. Full disclaimer .. It really is a highly recommended read. Caring for Children With Serious Neurological Impairment may be the go to publication. Hauer is an associate of the MLD Foundation's Medical & For the potential reader, if your child comes with an unknown neurological issue, I recommend this reserve. I work with these types of kids in the ICU and I found it interesting aswell. Having her wrapped up in a book (paper or digital) is certainly all the better![...] This is an excellent read for parents or caregivers of children with special ... This is a great read for parents or caregivers of children with special needs. We highly recommend this book for every and every parent and caregiver of a child with serious neurological impairment. help you understand different warning signs of medicine withdrawal or toxicity. It's the only resource I've EVER read that appears so be written just for my girl.. It is extremely medical with lots of terminology including medicine lists. I have shared pages of the book with various doctors and it has helped on a number of occasions, to greatly help us (parents and doctors) alter our goals and objectives to be more realistic and manageable.We strongly recommend this book for anybody caring for someone

you care about, of any age, with neurological impairment. While it's hard to think about end of life options, it helps to read about how various other parents possess approached it for their kids. Five Stars Very nice Great for parents Great for parents, well crafted with great explanations. We've known right here for a long time and she is usually a normal at our MLD Family members Conferences(tm) not because she wrote a reserve, rather it's because she knows her stuff and is definitely in a position to apply the technology and complexity of medication in a practical hands on way with family members. It really is written basic more than enough for caregivers but nonetheless provides relevance for nurses and doctors. Must read for parents of kids with severe impairments This book is crucial for parents of children with severe neurological impairment. This book was presented with to us by our palliative care doctor. It also provides you with here is how to connect with your son or daughter's care team because of this task being very hard at times. Dr. I am so thankful for her! This book was recommended to me by our pediatrician and it has been extremely helpful. It's been a lifesaver!



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