A JOHNS HOPKINS PRESS HEALTH BOOK

Caring for Children Who Have SEVERE NEUROLOGICAL IMPAIRMENT

A Life with Grace

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

Global impairment of the central nervous system, whether stable or progressive, is often called severe neurological impairment (SNI). A kid who provides SNI will be looked after both by professional clinicians and by parents at 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 and attention. Hauer advocates shared decision producing between family caregivers and healthcare companies. In Looking after Children Who Have Severe Neurological Impairment, Dr. She details areas of medical treatment such as pain, sleep, feeding, and respiratory issues that will be especially useful to parents. This guide provides information to greatly help parents increase their knowledge and improve their caregiving skills. Julie M. Tables and tips summarize discussions for clear, quick reference, while case studies and tales illustrate how different families approach decision making, conversation, care programs, and informed consent.mainly because can bioethicists and clinicians in pediatrics, neurology, physical and rehabilitative medicine, palliative care, and others who look after kids with neurological and neuromuscular disorders.Parents and other caregivers will find this book to be indispensable—Dr. Hauer offers wish and practical coping strategies in equivalent measure.

The ultimate go-to reference for caregivers of babies and children with severe brain disorders This book has been our go-to reference over the last couple of months, as we've coped with the various aspects of looking after our baby with epileptic encephalopathy and severe global developmental delay. Dr. Hauer provides comprehensive information on the full gamut of issues that come along with severe neurological disorders - not only seizures, but rather everything from feeding tubes to respiratory challenges to urine issues to autonomic dysfunction. Most important can be her professional and compassionate validation that quality of life is essential - and she provides research-backed info that helps caregivers make informed decisions about treatments and interventions, confidently and security. Even though reserve is targeted towards experts, as parents we have found it to be invaluable in assisting us to better realize why our baby encounters certain challenges and the various valid options for intervening - or not intervening - in each case... It really is written basic plenty of for caregivers but nonetheless has relevance for nurses and physicians. It has empowered me with knowledge about my children so I have more than simply my mom's intuition when I go to there many appointments. The 1st time EVER! We've recommend this for each and every MLD Family members we look after . Hauer, THANK YOU for taking the time to create this reserve. We tried among the suggestions in her publication and both my kids have slept through the night for two weeks straight! I desire there were even more loving and kind doctors like you. For the potential reader, if your son or daughter comes with an unknown neurological issue, I highly recommend this reserve. It is extremely medical with lots of terminology including medicine lists. Five Stars Excellent book for families of children with neurological conditions, have recommended to many other parents VERY USEFUL! and we utilize it when looking after our girl with MLD. It discusses some unfortunate topics like end of existence but it is unfortunately all necessary when you have a complex child. The best caregiver's guide for all those with neurological issues This book is written at a GP and specialist level nonetheless it quite comprehendible by most caregivers. It is a highly recommended read. Must have for parents of children with complex neurological problems I have two sons with an unknown neurologic genetic condition (SNI) and this book has been thus amazing it brings tears to my eye just writing this review.. Caring for Children With Severe Neurological Impairment is the go to publication.Finally a text written from the practical palliative care perspective - palliate care isn't end of life care, it's optimizing standard of living.We strongly recommend this book for anyone caring for a loved one, of any age, with neurological impairment. Dr. Scientific Advisory Plank.. However it is written for a caregiver, not a doctor.Dean Suhr, President, MLD Foundationp.s. Full disclaimer ... Dr. Five Stars Very nice Great for parents Great for parents, well written with good explanations.. This is an excellent read for parents or caregivers of children with special needs. Having her covered up in a reserve (paper or digital) is usually all the better![. We recommend this book for every and every parent and caregiver of a kid with severe neurological impairment..] This is a great read for parents or caregivers of children with special ... We've known here for years and she is usually a normal at our MLD Family members Conferences(tm) not because she wrote a book, rather it is because she understands her stuff and has always been in a position to apply the science and complexity of medication in a practical hands on way with family members. This book provide visitors 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. In addition, it provides you with information on how to communicate with your son or daughter's care team for this reason task being very hard at times. From medicine tables to fundamental neurology backgrounder, to strategies for pain administration, decision making, medical team development, and more . I have to look some conditions up online, but that is very important so you can speak your doctor's language. Plus, it's written by an expert in the field. It is the only resource I've EVER read that appears so be written just for my girl. While it's hard to think about end of life opportunities, it helps to read about how various other parents have approached it because of their kids. Hauer is an associate of the MLD Foundation's Medical & I use these kinds of children in the ICU and I found it interesting as well. My oldest has been in pain his whole life and although I suspected it, I never knew what to tell my physician who acquired no clue how exactly to treat it. Must go through 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 treatment doctor. I love the case studies and may find advice/input on almost every concern that has appear for my newly mind injured daughter. This book was recommended to me by our pediatrician and it's been extremely helpful. I am so thankful on her behalf! I've shared pages of the book with different doctors and it offers helped on several occasions, to help us (parents and doctors) change our goals and objectives to be more reasonable and manageable. It's been a lifesaver!

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