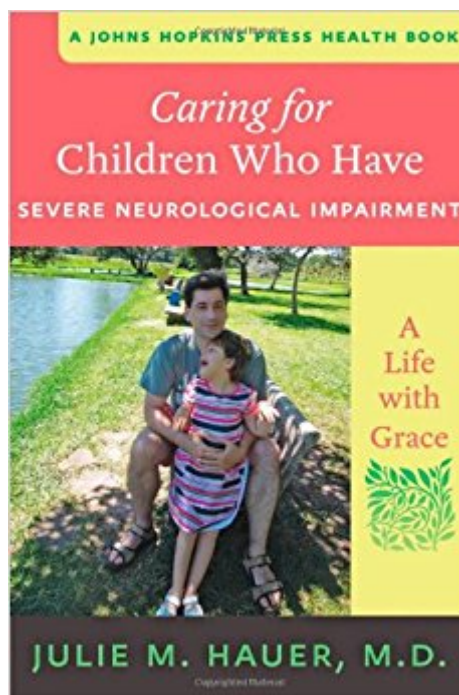


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# Caring For Children Who Have Severe Neurological Impairment: A Life With Grace (A Johns Hopkins Press Health Book)



## 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

"This unique book provides detailed scientific information that is carefully explained in a gentle and thoughtful manner. This book provides a much needed resource for families struggling to stay informed and make decisions for their children. It also is a new and essential resource for pediatric

palliative care professionals who walk alongside families as guides." (Jody Chrastek, DNP, RN, CHPN, Children's Hospitals and Clinics of Minnesota)"Framing by symptoms, not diseases, Dr. Hauer gives practical diagnostic and therapeutic approaches to the most challenging problems faced by children with severe neurological impairment. Grounded in compassion, experience, and family-centered care, *Caring for Children Who Have Severe Neurological Impairment: A Life with Grace* is a must-read." (Rishi Agrawal, MD, MPH, Academic Pediatric Association Complex Care Special Interest Group)"Julie's compassion for the struggles of families with children who have SNI and her concern for the quality of life of every patient who has SNI comes through. She conquers the complexity of combining all aspects of care—pain, GI, respiratory, spasticity, seizures, medications, end-of-life issues, and more—for patients who have SNI at all levels of involvement. Complex care issues combined with optimal quality of life information makes this a must-read for caregivers of those who have SNI—parents and clinicians alike." (Dean and Teryn Suhr, MLD Foundation)"The realities of children living with severe neurological impairments is two-fold: a side of difficulties and dark moments, and a side of joy and light. Dr. Julie Hauer attends to both sides in this book, as she has done for every patient and family she has encountered over the years of her career as an esteemed and beloved physician devoted to the care of children with major medical problems." (From the Foreword by Chris Feudtner, MD, PhD, MPH, The Children's Hospital of Philadelphia)" *Caring for Children Who Have Severe Neurological Impairment...* is the only book that has even made an attempt to tackle this difficult topic in any meaningful sort of way. The author has succeeded in creating what should become the caregiving Bible for any family of a child with severe neurological impairment regardless of diagnosis, or any medical provider for this population... The information provided, and the approaches recommended, are too important to be overlooked... *Caring for Children Who Have Severe Neurological Impairment: A Life with Grace* is highly recommended and should be on the bookshelf of every parent dealing with complex medical issues." (Susan Agrawal Complex Child)"For the health-care professional who provides care or interaction at any level to SNI patients, this book is a valuable resource. This is also a great resource to refer to family members and care givers. It helps with understanding and assists with developing questions for the health-care team. The family members reading this book will increase their abilities to advocate for their child's medical, social, and emotional needs. It provides tools and information that promotes dignity and respect for life in all its phases." (Marilyn Mills Journal of Radiology Nursing)

Julie M. Hauer, M.D., is an assistant professor, medical director of Seven Hills Pediatric Center, and

a staff member in General Pediatrics, Complex Care Service, at Boston Children's Hospital Harvard Medical School.

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.

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! [...]

This is a great read for parents or caregivers of children with special needs. This book provide 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.

This book was recommended to me by our pediatrician and it has been extremely helpful. I love the case studies and can find advice/input on just about every issue that has come up for my newly brain injured daughter. While it's hard to think about end of life possibilities, it helps to read about how other parents have approached it for their kids.

Very nice

Great for parents, well written with good explanations. I work with these kinds of kids in the ICU and I found it interesting as well. It is written basic enough for caregivers but still has relevance for nurses and physicians.

This book is so full of usefull information. Written in an easy to understand manner. A true must have for anyone connected with a child or adult with neurological impairment. I was fortunate to meet Dr Hauer at a conference and she is an amazing and caring person.

A lot of information, It would be very helpful for parents with children just diagnosed with any disorder, but after years of dealing with your child and the disorder you know most of the information in this book

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