Book Review:

*Caring for Children Who Have Severe Neurological Impairment: A Life with Grace* by Julie M. Hauer, MD

by Susan Agrawal

After reading most books about special needs that have been written by medical professionals, I typically have one of two reactions: incredulity or laughter. Most of them suffer from the same problem, which is that the authors simply have not lived the reality of life with a child who is medically complex. These books end up giving advice that those of us “in the know” recognize as ridiculous, because we’ve been there, tried it, and know the reality.

*Caring for Children Who Have Severe Neurological Impairment* by Julie M. Hauer, MD, is the rare exception. To be honest, it 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.

I first learned about Dr. Hauer after she published a study in 2007 in *Pediatrics*. This study discussed using Gabapentin (Neurontin) for children with extreme irritability and neurological impairment. I had spent the entire first year of my daughter’s life dealing with exactly what this article discussed--a baby with neurological impairment who cried 16 hours a day, every day. I fought her doctors for almost a year before they finally agreed to treat her pain with Gabapentin and another drug. Within just a few days, a new child emerged--a child full of smiles, ready to learn and explore the world around her. When Dr. Hauer’s article came out a few years later, I rejoiced to see a mainstream physician not only treating pain and irritability in children with neurological impairment, but also studying it.

Dr. Hauer has continued this unusual path of treating children with severe neurological impairment through much of her career. She is primarily a palliative care physician, and it is probably this very fact that makes her book--and her methods in general--succeed. She fully recognizes in the subtitle to her book, “A Life with Grace,” that children with severe neurological impairment are valuable and should be treated by medical professionals with dignity.
Unlike most books on children with neurological issues, Dr. Hauer is not interested in cures or acceptance or even therapies. She is thoroughly concerned with addressing all the medical issues that make our kids’ lives miserable. I personally spent about eight years of my daughter’s life figuring out—often by trial and error—much of the medical information that this book provides. I am thrilled to see all of that information compiled in one volume that is not only medically accurate, but also accessible to the average parent.

After an overview on neurological impairment, the bulk of the book discusses pain and other distressing symptoms. For many parents, this in and of itself is a miracle. So often we are told that pain and other distressing symptoms are just “the way it is” for kids with neurological issues. It is so refreshing to read a book where a physician says it is not OK for your child to be retching and vomiting all day long, crying in pain, or struggling to breathe. As parents, we know this intuitively, but the medical community far too often does not have enough experience—or compassion—to treat our children as they should be treated medically.

Dr. Hauer includes chapters on pain, gastrointestinal problems (retching, vomiting, feeding intolerance), respiratory problems (pneumonia, secretions, respiratory distress), neurological issues (spasticity, dystonia, dysautonomia, seizures), and what she calls “Changes from the Expected,” which includes problems with sleep, temperature, growth, and similar things. Each chapter begins by explaining why and how problems occur. Then Dr. Hauer offers a variety of different strategies, ranging from medication to surgery to lifestyle interventions, to treat the problem. She thoroughly accepts that there is not one right answer to any of these problems, and instead offers multiple suggestions, as well as vignettes that share patient stories.

The penultimate chapter of the book focuses on decision-making processes, a welcome and rarely included topic. As we all know, children with severe neurological impairment are quirky, and each and every decision must be considered carefully for each individual child. Dr. Hauer addresses decision making systematically, presenting concepts to consider, while never pushing any one particular approach.

The final chapter focuses on care at the end of the child’s natural life. While this topic may be difficult for many readers, it is something that many of us will need to confront now or in the future. It provides a general overview to the options available as children become sicker. For those families who are not yet at this point, this chapter can be omitted until it becomes more relevant.

The book is geared toward a wide audience, including both parents and medical professionals. Some parents may find some of the more medical sections of the book a bit difficult to understand, but care has been taken to explain and define terms and processes. On the other hand, physicians or other medical professionals may find sections of the book to be below their typical medical reading level. I hope they will read the book anyway, because the information provided, and the approaches recommended, are too important to be overlooked.
Some parents, especially those new to severe neurological impairment, may find the frame of reference of the book slightly off-putting. It is grounded in palliative care principles, which means that quality of life is always presented as more important than quantity of life. Some parents still trying to accept their child’s condition may find this psychically challenging.

*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.

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