



Raising a Child with a Neuromuscular Disorder: A Guide for Parents, Grandparents, Friends, and Professionals

Charlotte E. Thompson M.D.

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Raising a child with a neuromuscular disorder can be a overwhelming experience for even the strongest parent or grandparent. Dr. Charlotte Thompson, a leading authority in pediatric neuromuscular disorders, draws on her 38 years of experience treating children with muscular dystrophy, spinal atrophy, congenital and mitochondrial myopathies, Charcot-Marie-Tooth, and all the childhood neuromuscular disorders. Her book provides not only medical facts but much practical advice on how to cope with the many challenges of day-to-day parenting a child with neuromuscular disease.

Dr. Thompson discusses how to cope with the initial diagnosis of a neuromuscular disorder and then suggests ways to get beyond the shock, numbness, and anger that may occur. She describes each of the principal diseases giving the history, signs and symptoms, the usual course, outcome, genetics, and any possible treatments. Subsequent chapters offer advice on when to ask for a second opinion about the diagnosis, how to navigate the medical maze and work with a child's medical team. Tips on finding the most appropriate school placement and developing an individual education program (IEP) are invaluable. Dr. Thompson stresses the importance of taking one day at a time and insists that parents must care for themselves. She offers suggestions for developing family closeness and even how to make time for fun. Wise advice from parents of children with neuromuscular disease is inserted in boxes throughout the chapters. A large appendix gives resources state by state and country by country.

There is no training that prepares you to be the parent of a child with a disability, but *Raising a Child with a Neuromuscular Disorder* should be a great help to parents, grandparents, and anyone who cares for a child or young person.

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