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

Julie M. Hauer

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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.

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