

Pediatric Neurology Part III: Chapter 154. Medical and psychosocial considerations in rehabilitation care of childhood neuromuscular diseases (Handbook of Clinical Neurology)

Michel Vanasse, Hélène Paré, Reinhard Zeller

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Most neuromuscular diseases (NMD) are rare inherited conditions presenting a relentlessly progressive course. Some NMD are associated with intellectual impairment and many are complicated by musculoskeletal, cardiac, or respiratory problems. Rehabilitation care of NMD is thus best provided by a team of medical specialists and health professionals working closely together in an interdisciplinary fashion. Rehabilitation for patients with NMD should include physical evaluation but also assessment of their ability to manage their daily activities or work and their need for assistive devices. With appropriate physical, psychological, and social support, those patients can maintain a good quality of life and an adequate level of well-being. Surgical management of musculoskeletal problems in children related to neuromuscular disorders remains a highly controversial subject. This review is based mainly on the author's personal experience with conservative and periopeporative rehabilitation care for neuromuscular diseases. A multidisciplinary approach is advocated. The importance of proactive respiratory care is emphasized. Rehabilitation after surgical treatment of spinal deformities is analyzed outlining the particular aspects in spinal muscular atrophy, Duchenne's muscular dystrophy, congenital muscular dystrophy, and congenital myopathies. A disease- specific approach is recommended as the wide variety of different neuromuscular pathologies requires careful planning of treatment strategies best managed in a team approach.



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