

Preface

Children with complex cerebral palsy (CP) are an important group of children within the population of children who have CP and caring for them requires skilled management. What does “complex” really mean in this context? Children with medical complexity are defined as those who have chronic medical conditions often involving multiple systems, who have functional impairment and are often medically fragile or technology dependent. They are frequently high utilizers of medical resources. For the purposes of this book, children with complex CP are those children who have CP and who also have these features. Some might prefer to use the term “severe” rather than “complex” CP, and indeed both terms are utilized in this book. We did not edit out every single use of the term “severe” because it is still in common parlance and the label of “medical complexity” is relatively new. Our point is simply that complexity both encompasses severity and extends beyond it. CP is a common condition of childhood, occurring with a prevalence of approximately 2 per thousand live births. Precise data regarding the prevalence of children with complex CP is not available.

CP is a group of heterogeneous and complex disorders. It is the particular constellation of motor abnormalities, functional limitations, associated cognitive and sensory impairments, and secondary medical conditions belonging to each child that require thoughtful assessment by the clinician. The purpose of this handbook is to provide assistance to practicing physicians and related clinicians in meeting the challenges of assessment, care and management for children with complex manifestations of cerebral palsy.

In general, this book will pertain most to children who cannot walk unaided or independently. In the professional vernacular, this refers to the care of children in Gross Motor Function Classification System (GMFCS) groups III, IV and V. However, it is important to recognize that children with less profound neuromotor impairment at times can be quite complex as well, with significant intertwining needs. This definition of complexity thus encompasses a fairly broad and diverse group of children. The child with normal intelligence, communication, and oral motor skills with fair hand function who can walk indoors with a walker and manage a motorized wheelchair with a joy-stick in the community is quite different from the child with severe intellectual disability, impaired communication, exclusive gastrostomy feeding, and no independent mobility. The latter child is much more likely to have associated medical morbidities and even early mortality. However, all such children are complex and tend to represent outliers to the primary care physician or consulting pediatrician in that they are relatively uncommon in the general pediatric population and thus are not a familiar part of the typical physician's repertoire.

Caring for children with complex forms of CP is a rich and rewarding experience. It also demands breadth of medical knowledge and management of issues that fall outside of the traditional medical box. The former includes many predictable medical, neurologic, orthopedic, and functional concerns. The latter includes things such as helping families through the loss of having a "typical" child, living with the uncertainty of complicating factors, addressing the frustration of accessing much needed services, managing chronic pain, and more. By partnering with families and children, we can anticipate and identify concerns that may require evaluation or management. We can more effectively respond to acute issues if we have a knowledge of risk factors for an individual patient. We can advocate for our patients so that they receive the most robust services to help them achieve their potential. And in playing each of these roles in support of children with complex CP and their families, we get to know them well. The rewards are sharing in their triumphs large and small, and professional moments to savor.

The intent of this handbook is to be comprehensive, but in a practical way. Our aim is to "cover the waterfront" in terms of the issues that regularly face children with complex cerebral palsy, not in an exhaustive, encyclopedic fashion, but in a way that physicians and others will find useful in their practice. More specifically, our intent is to provide clinicians and consultants with the necessary tools to:

1. understand and conceptualize the child with complex CP,
2. evaluate or at least to begin to evaluate the array of secondary conditions and unique concerns common to complex CP,
3. directly treat or refer for treatment primary or secondary issues common to complex CP,

4. explain to families (even when consultants are evaluating or treating) what is happening with their child, and
5. to support families through the ups and downs of evaluation, diagnosis, prognosis, treatment options, decision-making, and outcomes.

The authors in this book are general pediatricians, sub-specialty care providers and therapists who have expertise and experience in caring for children and youth with cerebral palsy and related neurodevelopmental disabilities. Parents of children with CP and youth with CP are also authors. Their voices provide unique and critical wisdom for clinicians providing family-centered care, an essential practice in managing children with complex CP. The topics were chosen and organized to reflect current best practices in the developing world. Each chapter has a summary section of key points at the end for quick reference. Wherever possible, the information presented is supported by published evidence. Where published evidence is limited, the information presented is based on clinical experience and/or consensus of the authors and editors. In addition to the chapters, we have created an Appendix with tools to support clinical care and decision-making that we hope will help guide the practicing clinician in evaluation, management, preventive care, and crisis response.

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The Care Tools found in Chapter 23 are available to download at <http://www.mackeith.co.uk/shop/complex-cerebral-palsy-care-and-management/>