

Book Review

Children and Youth with Complex Cerebral Palsy: Care and Management, Laurie Glader and Richard Stevenson; MacKeith Press, 2019; ISBN-13: 978-1909962989, ISBN-10: 1909962988; paperback, 404 pp.

If you are a practicing clinician who specializes in caring for people with cerebral palsy, this book, *Children and Youth with Complex Cerebral Palsy: Care and Management*, is an excellent reminder of the breadth and depth of knowledge required to recognize and manage health issues about, promote continued health and function for, and consider quality of life in decision-making with patients and families. If you are a primary care clinician hoping to gain more knowledge about best practices in meeting the health needs of children with cerebral palsy (CP), the content is organized in a useful way by general and specific topics – but could also be considered overwhelming! The editors define this book to be a “handbook” that they hope will “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” (which they define as children within Gross Motor Function Classification System [GMFCS] groups III, IV, and V). Each chapter in this handbook provides detail and overview that can be helpful to busy clinicians. Most importantly, linking the science and art of medical care, all five learning objectives are skillfully met.

The editors, Laurie J. Glader MD and Richard D. Stevenson MD, have organized content over twenty-three chapters. The chapters cover a variety of topics – overarching matters, function-focused content, medical conditions, quality of life themes, and care tools. Each chapter offers particulars of health-related topics (most of which have an evidence-base) and key points that provide important summarized messages. Many chapters include illustrative flow charts, tables, and information boxes that encapsulate important concepts. Some chapters provide case studies, which bring an element of reality to the complexity of care. Additional resources include typical listed references and helpful

websites. In particular, care tools for clinical practice are illustrated at the end of the book and are available online with purchase of the book. These tools may be particularly useful to have parents annotate prior to a clinic visit.

Authors of chapters are the expected healthcare providers, who have expertise in the area of children and youth with cerebral palsy. In addition, authors are consumers of healthcare – young adults with CP and parents of people with CP who have interacted with health care professionals. The authors do a superb job of covering all the bases while advocating for a team approach to the care of families. The family is always assumed to be a part of the team. Obvious care has been taken to ensure that the person with CP and their family is the center of the healthcare experience. Using a qualitative approach, the chapter on growing up with CP provides a first-person thematic view of interactions with the healthcare team.

The organization of the topics may have related to the expertise of the authors in order to assure that topics could be found from a number of perspectives. Many authors provide an organization or structure to a topic based on their years of experience. These constructs can be useful, and readers should be encouraged to employ some or all of these within their own contexts. There is considerable overlap among chapters related to cognition, mental health, and behaviors. This can also be said to some extent for pulmonary issues with sleep behaviors, toileting behaviors with urologic issues, and feeding/nutrition with gastro-intestinal diseases. There is considerable attention given to the importance of and difficulty with shared decision-making. This topic is capably covered within the chapters entitled “Difficult topics and decision making,” “Through the eyes of parents,” “Evidence-based care,” “Transition to adulthood,” and “Growing up.”

The authors have provided evidence-informed recommendations where they are available. However in some areas, particularly orthopedic management, it is striking that we do not have evidence of functional improvement following treatment. Equipment needs are well covered, but there appears to be some partiality

to certain companies and limited details related to the science supporting use of the devices. The chapter on hypertonia provides an excellent overview of medical and procedural interventions, but with minimal discussion of the importance of post-treatment rehabilitation strategies particularly when function is the goal of the intervention. The emphasis of pain identification and management is on children with severe neurologic impairment, with little information about management for youth with less impairment than GMFCS V. Many chapters attempt to comment on a lifespan approach, although not all. In particular, some mention of incorporating health promotion would have been a welcome addition. Physical activity is recognized as an important element of health and people with complex cerebral palsy can and should participate in those activities. All clinicians, people with cerebral palsy, and their families should be aware of the concepts of fatigue, sarcopenia, obesity, undernutrition, and pain noted by children and adults with cerebral palsy.

This handbook is recommended for clinicians who work with children and young adults with CP and their families, whether the clinician provides specialty or

primary care. The editors and authors have worked to be comprehensive and yet practical in their presentation of the material. This is no easy task! The handbook is an excellent addition to a resource library.

Lynne Romeiser Logan PT, PhD, PCS
Program Manager

Tone Management and Mobility Program
Department of Physical Medicine & Rehabilitation
SUNY Upstate Medical University
Syracuse, NY, USA
E-mail: loganl@upstate.edu

Margaret A. Turk MD
Vice Chairman, PM&R

SUNY Distinguished Service Professor
Departments of Physical Medicine & Rehabilitation,
Pediatrics, and
Public Health & Preventive Medicine
SUNY Upstate Medical University
Syracuse, NY, USA
E-mail: turkm@upstate.edu