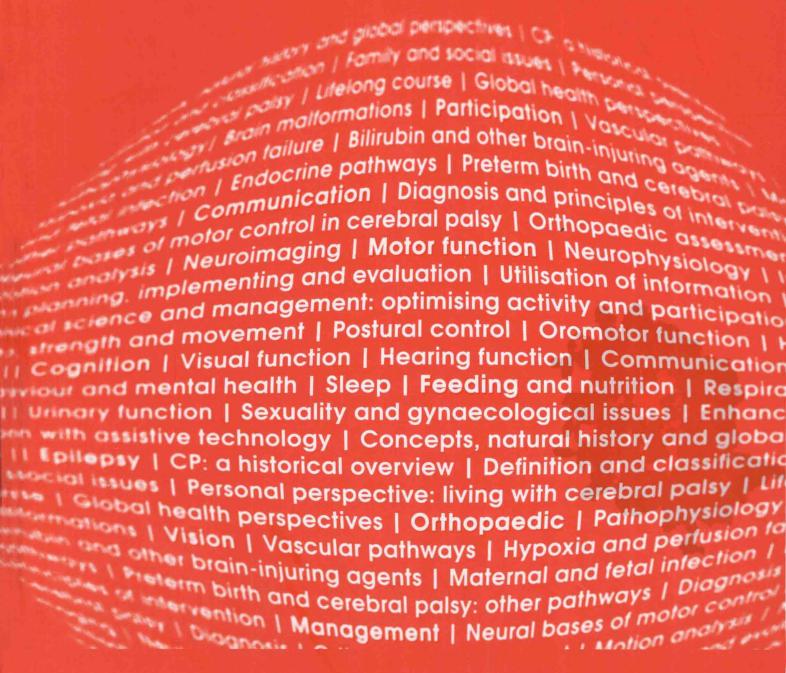


Cerebral Palsy

Science and Clinical Practice



Edited by **Bernard Dan**, **Margaret Mayston**, Nigel Paneth and Lewis Rosenbloom

Clinics in Developmental Medicine

Cerebral Palsy: Science and Clinical Practice

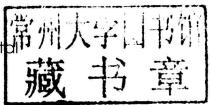
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Clinics in Developmental Medicine

CEREBRAL PALSY: SCIENCE AND CLINICAL PRACTICE

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FOREWORD

I am honoured to write the Foreword to this important and timely book on cerebral palsy (CP), the first comprehensive text dealing with this important neurodevelopmental disorder. CP is in some ways neglected compared with other developmental disabilities such as autism and Rett syndrome, yet children and their parents and adults with CP need information, advice, research, and advocacy on this complex cluster of disabilities that constitute the CP syndrome. Books like this one inform and encourage the CP world, and in an innovative section in this volume, provide the opportunity for their voices to be heard.

The editors include a Belgian neurologist, an American paediatric epidemiologist, an Australian physiotherapist trained in neuroscience, and a British child neurologist, and the book has chapters written by a diverse group of experts. The book illustrates how much such collaborations have improved our understanding of these conditions. Ambitious in scope, the book's four sections cover almost all that is currently known about this challenging motor disorder, and provide an excellent, up-to-date review of research findings.

Section One takes us from the definition and categorization of CP to the complex issues facing individuals with CP and their families. This section, in particular, will inform practitioners, and hopefully stimulate them to redouble their efforts in caring for families with CP. I hope that it may change community attitudes—promoting a greater appreciation of people with CP, increasing funding for both care and research, and increasing our understanding of what families of children and adults with CP face every day. The valuable chapter on the challenges in CP prevention and management in the developing world, which is where most CP occurs, should bring CP to the attention of those who finance health internationally.

Many individuals with CP and their families ask, 'Why did this happen to me/us?' This question led me to establish the Western Australia CP register – the first such effort in Australia – in the 1970s. A major concern then was that the increasing survival of preterm infants with the advent of neonatal intensive care might result in increasing rates of CP. This register enabled epidemiologists and clinicians to work together using clinical epidemiological approaches to the study of CP. From our long experience in Western Australia, we have found that successful research in CP is a product of assembling the most complete datasets from large and unselected samples, collaboration across clinical (paediatricians, allied health, obstetricians, neonatologists), epidemiological and pathological disciplines, and closely working with parents and families.

The editors have assembled just such collaborations here, and Section Two of this book brings leading thinkers in the field to ask the frustrating questions that must be asked if we are to understand the causal pathways to CP. Pathways to CP are many; indeed, more than one pathway may operate within an individual. The attempt to elucidate causal pathways is where we need the best and broadest collaborations—to learn how our parental genetic and epigenetic risks interact with early environments. Our understanding of the underlying pathophysiology has been enhanced by better biochemical data, improvements in neuroimaging, and more precise investigations of maternal and fetal risks, amongst others, but we still do not know enough. Our frustrations are largely due to our inability to measure key events at key developmental stages. We still rarely know what really happened to cause CP in a particular person. For parents this section will be challenging. But it may stimulate clinicians and scientists to continue to ask the relevant questions.

Another question families ask is, 'What can we do to maximise our child's potential?'. This question is well answered in Sections Three and Four. The wealth of new information and thinking in the chapters of Section Three provide some of the best contributions of the whole book. It is here that we start to comprehend the natural history of CP, how the brain changes during development, and how this knowledge can be used to help care. The importance of gait analysis and new brain assessments is clear and has implications for what we need to lobby for in centres of excellence offering care. Siddhartha Mukherjee has described, in his book *The Emperor of All Maladies*, the disastrous mutilating surgery once done in ignorance of cancer biology. Sharing of knowledge across disciplines should enable us to use the best and most rigorously evaluated interventions, while following the ancient principle 'First, do no harm'.

Section Four, the final section of the book, is a bible for clinicians and a vital resource for parents, families, and individuals with CP. Written with sensitivity, it contains a comprehensive set of chapters on all the disabilities that people with CP can have. Mental health and other conditions not specifically related to the core CP diagnosis are important components. The chapter covering relationships and sexuality is especially useful.

The Clinics in Developmental Medicine series published by Mac Keith Press (named after a beloved UK clinician who focused his energies on CP) have made a major contribution to our understanding of developmental disorders. This book is a worthy addition to this series. Ronnie Mac Keith would have loved it.

Professor Fiona Stanley School of Paediatrics and Child Health The University of Western Australia

PREFACE

The Editorial Board of Mac Keith Press has long considered that a reference work on cerebral palsy (CP) should be an integral component of its list of publications. The Press is uniquely positioned to produce the seminal work on CP for clinicians and other professionals looking for a comprehensive volume that integrates coverage of scientific foundations together with the principles of clinical practice across the range of functions involved in CP. Thanks principally to Hilary Hart, this book project has been fully realized and is effectively the last major publication of Mac Keith Press that she will see to fruition before her retirement from the Press. The concept of this reference work never disappeared from her 'to do list'.

It was not really a coincidence therefore that she has been able to bring together the four of us as editors and to facilitate our cooperation in all of the work involved. At the same time, the desire to produce a major work on CP has been a factor in the thinking of all four of us over a number of years. We were delighted to have had the opportunity to work together in firstly agreeing what this book should contain, secondly to commission the many contributions who were required, and thirdly to synthesize and edit these into what we hope will be both a 'much loved book on CP' and a useful, up-to-date, and enduring reference work. As editors we have each brought our range of knowledge and professional experience into this mix. We are also very grateful indeed that the contributors, all of whom are noted experts in their fields, have participated willingly and promptly, and that they have coped with and responded to our editorial requests and challenges. In addition each of us has contributed to the writing of several individual chapters.

As Professor Fiona Stanley has written in her Foreword, CP with its range of manifestations has not been given the attention and investment that other developmental disorders have received lately. We hope that this book will go some way towards remedying this shortfall within the context of other initiatives. These range from the widespread acceptance of the International Classification of Functioning, Disability and Health of the World Health Organization, slowly changing societal attitudes towards disability, and the work of bodies such as the National Institute for Health and Care Excellence in the UK, the Agency for Healthcare Research and Quality in the USA, or the American Academy of Neurology in producing best-evidence statements and guidelines for CP.

Readers will quickly become aware that we have attempted to be systematic in using the 2007 (Rosenbaum 2007) definition of CP and the classification proposed by the Surveillance of Cerebral Palsy in Europe (SCPE) (Platt et al. 2009). To move away from terms such as quadriplegia and diplegia has not been without its challenges both to the editors and to many of the contributors, not least because so much of the literature on which we rely uses this nomenclature. We are nevertheless pleased to have undertaken this development as it has also enabled us to use current classification systems systematically such as the Gross Motor Function Classification System, the Manual Ability Classification System, the Communication Function Classification System, and the Eating and Drinking Ability Classification System.

CP as a condition is a priority for health programmes globally, but we have little firm knowledge of its frequency in developing nations. However, five reviews of the prevalence of CP in developed countries published from 1981 to 2013 (Kiely et al. 1981, Paneth and Kiely 1984, Bhushan et al. 1993, Paneth and Korzeniewski 2006, Oskoui et al. 2013) concluded that CP occurs at a rate of about 2 per 1000 live births, although a recent US study puts CP prevalence above 3 per 1000 school-age children (Christensen et al. 2014).

One challenging issue to us has been the increasing appreciation that there are many more adults than children who have CP, but that useful studies about adults have been rare. In part this is because CP in adults does not usually present as a developmental, health or educational problem. We have nevertheless attempted to consider the lifelong course whenever it has been practicable to do so. In addition to the professional expert views, we thought it was important to present the perspectives of three individuals with CP as told in their own words or, in one case, in the words of a child's mother.

In clinical practice, causal pathways in CP are complex and usually interrelated. As editors we have been influenced both by epidemiological studies and by the wide range of clinical and laboratory data that have come increasingly on stream. It is worth reflecting that had this book been written 20 years ago this section would have been very different indeed. The same may also be said if it were written 20 years hence! These points are well illustrated if we consider the rapidly developing world of neuroimaging, or if we examine our increasing knowledge about the risks to the brains of preterm infants, or how cooling modifies responses in the brains of asphyxiated infants at term to reduce the risk of CP.

As is appropriate in any text on this subject, we have considered, as part of the clinical presentation of CP, the nature of the motor disorders in detail. This includes their assessment and the range of therapeutic, medical and surgical interventions that are available. We also make clear that these apply to all voluntary muscle groups including those concerned with ocular or oral motor function. We have also been keen to ensure that an up-to-date evidence base for the opinions and recommendations in these chapters has been critically assembled.

Preface

But CP is much more than a motor disorder. We have been concerned to include authoritative accounts of associated developmental impairments and of related health issues. The former includes the chapter on behaviour and mental health issues of which Gregory O'Brien is first author. We are very sad to record that Professor O'Brien died in July 2014. He was an esteemed friend and colleague, and a staunch supporter of Mac Keith Press.

We have tried throughout to focus on people with CP and their families, to be aware of their lifetime needs and to consider both immediate and longer-term issues of adaptation and participation. We have also included many vignettes set in various clinical contexts to illustrate selected aspects developed throughout the book.

Professor Stanley in her Foreword has said that Ronnie Mac Keith would have approved of our efforts. We do hope so, and we would add Martin Bax's name to his as one who has influenced our thinking on CP during the course of our careers. We are grateful to both of them for their pioneering work both on CP and for Mac Keith Press.

The book could not have been completed without the support and energy of Udoka Ohuonu, Hilary Hart, Alessy Beaver, Ann-Marie Halligan, and of course Chris Purdon. It has also been helpful to receive the informed comments of many members of the Editorial Board of Mac Keith Press. In addition all of us as editors have thrived and learned from one another and we have appreciated the opportunity to work as a team of friends. We shall miss our intercontinental telephone conferences.

Bernard Dan, Margaret Mayston, Nigel Paneth, and Lewis Rosenbloom

August 2014

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TERMINOLOGY

Classification of cerebral palsy: Topography and motor type is defined in this book according to the classification of the Surveillance of Cerebral Palsy in Europe (SCPE) (see Chapter 2).

Other accepted terms (hemiplegia, diplegia, and quadriplegia) are placed in brackets after the SCPE term where they are used in cited research papers.

Intellectual disability is used for an individual with an IQ<70, replacing the terms 'mental retardation' and 'learning disability/ disabilities' (UK).

Botulinum neurotoxin-A/B is used instead of botulinum toxin (BoNT-A/B), as specified by the International Council on Neurotoxins and the Neurotoxin Institute.

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