

*“A must-read for
professionals, parents,
and the individual
with CP”*

— DEBORAH
GAEBLER-SPIRA, MD

SPASTIC DIPLEGIA BILATERAL CEREBRAL PALSY

Understanding the
motor problems,
their impact on
walking, and
management
throughout life: a
practical guide
for families

Lily Collison MA, MSc
PARENT

Edited by
Jean Stout, PT, MS
Amy Schulz, PT, NCS
Candice Johnson, OTD, OTR/L
Tom F. Novacheck, MD

GILLETTE CHILDREN'S SPECIALTY HEALTHCARE

From the reviews of *Spastic Diplegia—Bilateral Cerebral Palsy*
Full reviews available at www.GilletteChildrensHealthcarePress.org/sdbook

This book provides the answers we have all been looking for ... the perfect balance of science and practical knowledge ... With a resource of this quality, the future is bright for all of us.

DR. LINDA A. HALLMAN, parent of teenager with spastic diplegia, Director of Orthodontics, MedStar Washington Hospital Center and Children's National Medical Center, Washington DC, USA

This co-developed parent-professional book on the focused topic of spastic diplegia is a must-read for professionals, parents, and the individual with cerebral palsy (CP). The range of the book is "real-world focused" with the latest accurate literature incorporated ... It serves a unique educational niche ... I am recommending it already!

DR. DEBORAH GAEBLER-SPIRA, Director Cerebral Palsy Program, Shirley Ryan AbilityLab, Professor of Pediatrics and Physical Medicine and Rehabilitation, Northwestern Feinberg School of Medicine, Past President, American Academy for Cerebral Palsy and Developmental Medicine, Illinois, USA

This book is excellent, insightful, and educational: it will open minds and touch hearts. It is very clear and easy to read. As an adult with spastic diplegia, I have learned many new things about my condition from reading it.

SAMANTHA MARIE LADEMANN, adult with spastic diplegia, Minnesota, USA

This book provides a comprehensive overview of all aspects of living with bilateral spastic CP ... The combination of evidence-based information and personal experience ensures that this book is an engaging and thought-provoking read, which families and health professionals would benefit from owning.

DR. JENNIFER RYAN, Research Lecturer, Royal College of Surgeons in Ireland (RCSI), Dublin, Ireland

I met Lily Collison for the first time in mid-September 2001, when I was lecturing at a cerebral palsy seminar held at the Central Remedial Clinic in Dublin, Ireland. Lily later brought Tommy to Gillette ... for treatment. That began a doctor-patient relationship that lasted up until my retirement in 2008, and a friendship that has lasted to this present day. Lily wrote a book for parents, much as I did for orthopedic surgeons back in 1991. This book, Spastic Diplegia—Bilateral Cerebral Palsy ... is a must-read for parents of children with spastic diplegia, and if its guiding principles are followed, it will do much to ensure that their particular child reaches maturity with an optimal outcome.

DR. JAMES R. GAGE, Medical Director Emeritus, Gillette Children's Specialty Healthcare, Past President, American Academy for Cerebral Palsy and Developmental Medicine, Professor of Orthopedics Emeritus, University of Minnesota, USA

Lily Collison and the staff at Gillette have taken a very complex disorder—spastic diplegia—and made it comprehensible to the lay reader. CP is a disorder that many clinicians do not fully understand either. As a pediatric orthopedic surgeon who specializes in the care of children and adults with CP, as well as being the father of a 37-year-old man who has CP, I highly recommend this book to people who have CP, parents, family members, and medical professionals. It is a fantastic overview of the subject with many insightful passages by those who have taken the journey.

DR. HANK CHAMBERS, Professor of Clinical Orthopedic Surgery, University of California, San Diego, Director of the Southern Family Cerebral Palsy Center at Rady Children's Hospital, San Diego, Past President, American Academy for Cerebral Palsy and Developmental Medicine, California, USA

This book is beautifully balanced—from references and information, to the heart of a mom lighting the way for other parents struggling to filter an overload of information ... I would have loved to have had this book at the time of our son's diagnosis, and would recommend any family members to also read it for a much deeper understanding of CP and how to help the family and child with CP ... What a gift you have written.

CARY SOMMER, parent of an eight-year-old with spastic diplegia, Minnesota, USA

Health care is at its best when the patient is at the heart of health services. One of the fundamental components in this process of patient participation is sufficient knowledge about the disease and its treatments. This will allow good communication and making informed choices about treatment. This book provides that knowledge ... For patients with spastic diplegic CP and their families this book provides a perfect start to become equal partners in their health care decisions.

DR. ANJA VAN CAMPENHOUT, Pediatric Orthopedic Surgeon, University Hospital Leuven, Belgium

As I read this book I found myself changing hats; one minute I was reading it as a GP, the next minute I was reading it as the mum of a son with a disability. The scientific and medical content of the book is excellent, and I learnt a lot by reading it ... For a parent of a child with spastic diplegia, this book is an incredible resource. I would have loved one about spina bifida 21 years ago.

DR. SIOBHÁN TEMPANY, GP, parent of son with spina bifida, Ireland

This book is a valuable addition to the CP literature ... A particular strength of the book is the road map that is outlined as the child with CP grows from infancy to adulthood ... The addition of reliable and user-friendly web links is very helpful for the reader.

DR. OWEN HENSEY, Medical Director, Central Remedial Clinic, Dublin, Ireland

This is a wonderful resource for people with spastic diplegia and their families, which draws robust scientific information together in a clear and accessible way ... Teamwork between health professionals, the person with CP, and their family is essential to achieve the best management plan ... This book supports the voice of the person and parents in the team, empowering shared decision-making ... a must-read for people with CP, families, health professionals, and students alike.

DR. CATHERINE BLAKE, Dean and Head, UCD School of Public Health, Physiotherapy and Sport Science, Dublin, Ireland

I needed this book when my son was born almost 15 years ago and didn't meet his developmental milestones ... I needed it when I was conducting my own research without the skill set on what intervention he needed when he was seven years old. I need it now as he ages and has growth spurts and we are researching orthopedic procedures. I will need it when he becomes an adult and lives independently.

LORI POLISKI, parent of teenager with spastic diplegia, Marketing Manager, Cerebral Palsy Research Network, Washington, USA

Although we are in a low-resource setting, the team working with children and families ... strives to provide the best care possible. Much of what has been described in this book is not yet available here, but the desire to improve options for care is honest and committed. This book, although written for families, has the potential to have a great impact on health care professionals and other stakeholders who have the ability to work on improvements at a more global level.

SUE MURR, Physiotherapist, Uganda

Thank you, Lily, for providing such an accessible resource for so many people, the person with spastic diplegia, their parents and families, medical professionals, and education professionals like me who prepare teachers to work with children with CP. I will certainly be using it to inform my practice with my students. This book should be on so many people's reading list!

DR. ANNE O'BYRNE, Lecturer in Inclusive Education for Children with Special Educational Needs, Mary Immaculate College, parent of adult with disability, Limerick, Ireland

As a personal trainer who has multiple clients with physical challenges and CP, this book brought a whole new level of insight into what my clients have experienced ... Rich in encouragement, scientific knowledge, practical advice, and personal stories, it will deepen your empathy and drive to achieve fitness for clients with physical disabilities.

VANESSA LIU, Personal Trainer whose father has CP, California, USA

A must-read for anyone working with young athletes with CP. This masterfully written book weaves together a wonderful spirit of optimism with practical tools for parents, educators, coaches, and medical professionals. As we look to grow the Paralympic movement in the United States, Lily's work is critical to elevating the level of development programs available to young Paralympic hopefuls.

KARA BUCKLEY, Director, U.S. Olympic and Paralympic Properties (USOPP), California, USA

This is a unique book which gives an excellent insight into and holistic understanding of ... spastic diplegia ... from birth to adulthood ... This book will assist any parent or relative of a child ... or indeed a young person themselves in understanding their condition ... and, most importantly, what they themselves can do to influence outcome ... This book should also be read by all professionals working with persons impacted by disability and specifically CP.

MIKE WALSH, Head of Specialist Services and Research, Central Remedial Clinic, Dublin, Ireland

This book ... is a fantastic resource for parents and professionals alike ... I wish that an equivalent book might soon be written for hemiplegia.

EIMEAR GABBETT, parent of an eight-year-old with hemiplegia, Ireland

I compliment the author of this amazing "sat nav" for parents, siblings, families, carers, and teachers who may be setting out on a care journey of a young person with ... spastic diplegia ... I don't think there is anyone who wouldn't benefit from reading this book.

UNA COLLINS, teacher of children aged four to 13, whose sister has a disability, Ireland

When someone important to us is living with a long-term health condition, we often want to know what we can do to help. However, locating accurate, easy-to-understand information, specific to our needs, is not always easy. Parents and caregivers of children living with spastic diplegia will find this book provides them with such information.

DR. DÉSIREE B. MALTAIS, Associate Professor, Rehabilitation Department, Université Laval, Researcher, Centre for Interdisciplinary Research in Rehabilitation and Social Integration, Quebec City, Canada

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CEREBRAL
PALSY**

REVIEW COPY

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For specific medical advice and treatment, please consult a qualified
health care professional. The information in this book is not intended as
a substitute for consultation with your health care professional.*

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Foreword

I have known Lily Collison since 2010. I first knew her as a concerned and dedicated parent of a child with spastic diplegia seeking advice about the best treatment approaches. She had sought care at Gillette Children's a few years earlier; now her adolescent son, Tommy, was having intractable knee pain and she hadn't found answers closer to home. Thankfully, we were able to work through that problem. We stayed connected as I continued to see Tommy through to the present day. During that time, Lily has applied her knowledge and experience to firmly advocating for the development of resources for and the dissemination of knowledge to families and patients. She and I have worked together on projects that have supported our gait lab, Gillette-based research, and the communication of awareness and knowledge.

When Lily first mentioned that she thought there should be a book like this for spastic diplegia—bilateral cerebral palsy (CP) and that she was willing to write it, I was unsure and skeptical. However, she made a strong case for it. After investigating the resources available to parents whose child has been diagnosed with CP, I found that she was indeed right. Parents are left mainly to self-educate from various piecemeal resources—books (limited in number), websites, pamphlets, handouts, etc. The variability of the condition and its causes, delayed diagnosis, and misinformation litter the playing field, causing bewilderment and frustration.

Lily's background as both a parent and medical sciences graduate made her an ideal person to write this book for families. She has been dedicated to understanding this condition and the treatment options available since her son was first diagnosed. She dearly wants others to have an easier path than the one she experienced as she gained the knowledge to advocate for her child. Through what she learned over the years and her detailed research, and with support and editorial review from staff at Gillette, she has delivered this comprehensive and comprehensible book, which you will be able to use as your child

grows right through to adulthood. She has balanced the scientific information with personal anecdotes and stories from a variety of others whose lives have been affected by CP.

This is a unique book; it tells not only the detailed technical story of spastic diplegia but also the human story of the condition. This is a valuable book; in fact, it is so well done that it could be a resource not only for parents but also for health professionals in the field. I have learned much by listening to Lily and other parents like her ... and to their children. Lily's experience was of spastic diplegia, and this is what she has written about. Although spastic diplegia is only part of the spectrum of CP, it is one of the most common forms. In addition, many of the principles in this book can be applied more broadly to other forms of CP because the child's growing body can be similarly affected.

As you read this book, you will wonder how a parent could write such a comprehensive book about this medical condition, but Lily has skillfully done so. When I first read the full book, my reaction was, wow! This is a unique gem; it hits a target that has not been struck before.

Dr. Tom F. Novacheck

Preface

*Education is the most powerful weapon
which you can use to change the world.*

Nelson Mandela

If you are reading this book, most likely you are the parent of a child with spastic diplegia or you yourself have the condition. You may have a family member, friend, or student with spastic diplegia, or you may be a professional working with people with the condition. Spastic diplegia, also known as bilateral spastic cerebral palsy (CP) or simply bilateral CP, is a subtype of cerebral palsy. It is a lifelong condition characterized by limb muscles that are extremely tight (spastic) with the legs more affected than the arms (diplegia). However, spastic diplegia involves much more than tight leg muscles. This book provides a detailed explanation of spastic diplegia and shows how the condition develops over time. It describes the best management and treatment of the condition (at the time of writing) in childhood, adolescence, and adulthood.

My third son, Tommy, was born at term in Ireland in 1994. His older brothers, then aged four and six, had been easy babies, so by then my husband and I felt quite relaxed as parents. Tommy was born after an uneventful pregnancy and delivery, but from birth he cried incessantly. At three weeks our family physician insisted that I give up breastfeeding. She could see how frazzled I had become due to Tommy's constant crying, his difficulty with feeding (many feeds were being returned), and the fact that neither he nor I was getting much sleep.

At three months the incessant crying suddenly stopped; Tommy became a serene, happy, and placid child, and we all relaxed again. However, a few months later, at a routine developmental check, he was deemed "developmentally delayed." That started a long journey, beginning with the diagnosis of spastic diplegia when he was a year old and continuing with the management and treatment of his condition in our community

as well as at the Central Remedial Clinic (CRC)¹ in Dublin. In the early years he also received conductive education,² and in adolescence he had a number of surgeries at Gillette Children's Specialty Healthcare (hereafter referred to as Gillette) in Minnesota. At the time of writing, Tommy, now 25 years old, is a college graduate, working full-time and living an independent life in the US.

Why a book on spastic diplegia is needed

CP is the most common cause of lifelong, childhood-onset physical disability in most countries, with an estimated prevalence of 17 million people worldwide [1]. Approximately one-third of those with CP have spastic diplegia [2]. Spastic diplegia is thus a common subtype of CP, affecting an estimated 6 million people worldwide—roughly the population of Ireland. If this book helps a tiny fraction of those affected by spastic diplegia, writing it will have been worthwhile.

A book on spastic diplegia that is accessible to laypeople does not exist. It did not exist when Tommy was diagnosed almost 25 years ago, and it still does not exist today. Many of the specialist centers that treat CP now have well-developed websites, but again, they do not offer much information specific to spastic diplegia.

Good texts on CP exist, but many cover all subtypes of CP together.³ Explaining the different subtypes together is like having one book to explain all types of cancer and their treatments. Each subtype of CP is different, and each has a different prognosis for mobility and associated health challenges. Subtypes vary from generally mild to severe. Anyone with a condition is understandably rather selfish—they only want to learn about their specific condition. If my diagnosis is throat cancer, I only want to learn about throat cancer. If my diagnosis is spastic diplegia, I only want to learn about spastic diplegia. I do not need to know about health challenges that do not concern me.

¹ The Central Remedial Clinic (CRC) in Dublin is a national treatment center for people with physical disabilities.

² Conductive education is based on an educational rather than a medical model for treatment of children with CP. It combines educational and rehabilitation goals into a single program [3].

³ The subtypes of CP are spastic CP (monoplegia, hemiplegia, diplegia, triplegia, and quadriplegia), dyskinetic CP (dystonic and choreo-athetotic), ataxic CP, and mixed CP. These terms are fully explained in section 1.6.

Spastic diplegia is complex. How can a baby born with what appear to be typical bones, muscles, and joints grow into the young child who may walk with a gait⁴ typical of a child with spastic diplegia? Although spastic diplegia is a complex condition, it becomes more understandable when logically explained.

Spastic diplegia is a lifelong condition, and we parents are key influencers of outcomes. My lack of understanding always held me back. My background is in science, and I was thirsty for knowledge that would further my understanding of the condition. In those early days, before the internet had become the resource it is today, I scoured bookshops in any city I visited, but all I could find were books on CP in general. The first book I found that offered specifics on spastic diplegia was one written by Dr. Jim Gage (1991), an orthopedic surgeon at Gillette who has since retired [4]. (This book was recommended to me by Tommy's community physical therapist, who had previously worked at Great Ormond Street Hospital in London and had visited Gillette.) Though I learned a lot from it, this book was not fully accessible to me because it was written for medical professionals. It took me many hours and much hard work to find the information I needed to understand the condition. That hard work culminated in my completing a master's degree over a decade ago—a case study providing a detailed picture of single-event multilevel surgery (SEMLS)⁵ and rehabilitation, and evaluating outcome.

This book seeks to provide you, the reader, with an understanding of spastic diplegia without having to invest so much time and effort. Indeed, Bailes and colleagues (2018) pointed out that most of the time, health professionals underestimate the amount of information parents and caregivers want about their child's condition [5]. This problem extends to adulthood: lack of information about their condition was the highest area of unmet need reported by young adults with CP [6]. This included information on complications, consequences, and causes of CP.

The parent of a child with spastic diplegia does not have the full, long-term view of how spastic diplegia develops over time. Medical professionals have the benefit of their training and their clinical experience to put

⁴ Gait is a person's manner of walking.

⁵ Single-event multilevel surgery (SEMLS) involves multiple orthopedic surgical procedures performed on the lower limbs during a single operation.

things in context, but a parent does not. In the early days, I felt like I was trying to do a jigsaw puzzle without having the picture on the box as a reference. I had pieces but did not understand how they fit together. I wanted to help my child walk, but his physical therapist wanted me to help him roll.

A good explanation gives us parents a much better understanding of what we can and cannot change about our child's condition. Greater understanding should give us more confidence when helping our child. I so often had doubts: "am I doing this correctly?"⁶ Greater understanding should lead to greater motivation to carry out the exercises we are given to do at home.

Parents also put in a huge effort to prevent future possible events—events of which we have no experience. Success is avoiding negatives. In some ways, that feels unsatisfactory. I'd never seen the problems resulting from excessive W-sitting;⁷ they were as vague to me as being told as a young Catholic child, "Don't do this or you won't go to Heaven." Heaven was vague to the younger me. Hip subluxation⁸ and contractures⁹ were vague to the older me. I'd never seen them, nor the problems they caused. People who have plenty of money do not really understand the pain of poverty. People who have plenty to eat do not really understand the pain of hunger. People who already understand do not really feel the pain and frustration of just not understanding. Many prospective parents read books such as *What to Expect When You're Expecting* [7] to understand the different stages of pregnancy; this book could just as easily be called *What to Expect When You or Your Child Has Spastic Diplegia*.

Having a book just for spastic diplegia protects against unnecessary anxiety. Books and websites on CP frequently include a long list of other possible problems separate from the movement disorder, such as epilepsy or learning disabilities. However, the presence of other prob-

6 Regarding elements of the home program, for example.

7 "W-sitting" is the term used to describe the sitting position which the child with spastic diplegia (and other forms of spastic CP) adopts. The child's bottom is on the floor while their feet are out. Looking from the top, the legs form a "W" shape.

8 In a subluxated hip (hip subluxation), the ball is partially out of the socket but is still in contact with it—the ball is still partially covered by the socket.

9 A contracture is a limitation of the range of motion (ROM) of a joint.

lems largely depends on the CP subtype. Generic lists are not helpful and cause unnecessary anxiety for us parents, who already have enough to worry about. The opposite also holds true: if I have a child who is unlikely to ever walk independently, what use is it to read about gait analysis?

On the subject of anxiety, some may argue that if parents read this book—a book which details the issues associated with spastic diplegia in childhood, adolescence, and adulthood—they will not be able to handle the full story and will become even more anxious. I disagree. I would counter by noting that we parents find out quickly that our child’s spastic diplegia is not going to go away. We see adolescents and adults with spastic diplegia in treatment centers and in the community, which gives us an idea of how the condition develops. Ignorance is not bliss. Fear of the unknown can be a bigger problem. Indeed, if we are given the long-term picture of how our child’s particular condition will develop, it may be better than we fear. It may also mobilize us to early action. Outcomes in adulthood very much depend on management and treatment in childhood and adolescence (though spastic diplegia also presents its own challenges in adulthood). If you are a parent of a young child with spastic diplegia, I would advise you to read this book in full now, including the chapter on adulthood, to gain a full-life perspective on the condition.

Despite their best efforts, medical professionals use medical terms. This is a new language for us parents; we’re not familiar with terms like “adduction” and “dorsiflexion.” Professionals can either refrain from using such terms or continually explain them to parents. Alternatively, parents can gain an understanding of these commonly used terms. I think the latter is much easier all-around. This book includes an explanation of this “new” language for parents.

Treatment of CP does not involve just one discipline. It involves professionals from a number of disciplines, including physical therapy (PT, also termed physiotherapy), occupational therapy (OT), speech and language pathology/therapy (SLP/SLT), nursing, orthotics, pediatrics, neurology, neurosurgery, orthopedic surgery, and physical medicine and rehabilitation (PMR, also termed physiatry).¹⁰ Within the multi-

¹⁰ These disciplines are explained in the glossary.

disciplinary team, no one professional is responsible for explaining the condition to parents; it is very ad hoc. At appointments, there is little time for explanation because the child is present and their treatment takes priority. (In addition, the child will get bored if the adults are talking too much.) Having medical professionals explain the condition to parent after parent is inefficient. It would be preferable, in my opinion, to have well-developed resources available to parents, and professionals can then answer specific questions.

Parents are co-decision makers with medical professionals. Unless we have a good understanding of the condition, how can we contribute in a meaningful way to this very important process? How can we be effective advocates for our child? A survey of 1,214 parents and caregivers of children with CP found that they judged available medical information to be inadequate to guide their decision-making [8]. Educating the parent is investing in a most vital member of the child's multidisciplinary team. Obviously, in time the role of the parent passes on to the adolescent—and then the adult—themselves.

How can we know if our child is getting the best management and treatment if we don't know what best management and treatment looks like? In an ideal world, management of spastic diplegia for all individuals would be at the current limits of medical science. This book details the best treatments available and the evidence base supporting each one. I regret that I did not know about selective dorsal rhizotomy (SDR)¹¹ back when it would have been a treatment of choice for Tommy. (For a number of reasons, the “ideal” candidate for SDR is aged four to seven years; reasons include that secondary contracture development is still minimal. By the time I learned of SDR, Tommy was nine and had already developed contractures.)

Parents are also bombarded with treatment ideas from well-meaning family and friends. In addition to describing evidence-based treatments, this book includes information on treatments that have been disproven or still lack an evidence base.

¹¹ Selective dorsal rhizotomy (SDR) is an irreversible cutting of nerve rootlets in the spinal cord to reduce spasticity.

This book also explains the expert consensus on the best management plan for spastic diplegia. I would encourage readers to ask about their center's management plan, which may not exist—but if it doesn't, asking about it puts pressure on centers to develop one. I also hope that this book puts pressure on centers to provide the best evidence-based treatments—or, in their absence, to facilitate access to centers where such treatments are available. Treatment should not be limited by zip or postal code.

The world is changing. In all areas of medicine, patients now want good information. This book is motivated by that drive.

How this book was written

I was convinced of the need for this book but was not sufficiently knowledgeable or qualified to write it alone. I proposed the idea to Dr. Tom Novacheck at Gillette, and I am eternally grateful that he understood the need. Under his stewardship and with the great help of Jean Stout, Amy Schulz, and Candice Johnson, this book exists today. Indeed, this book bears testament to the fact that at Gillette, parents and professionals work well together.

The title of this book is *Spastic Diplegia—Bilateral Cerebral Palsy*. Throughout Tommy's life, the term “spastic diplegia” was used to describe his condition, and this term remains in use in the US today. Over the past 20 years, the term “bilateral¹² spastic CP” or simply “bilateral CP” has been adopted in Europe and Australia because it is thought to provide a more accurate description of the condition. If Tommy were diagnosed in Ireland today, his condition would be called “bilateral CP.” Indeed, all three terms are used in the scientific literature.

The Gross Motor Function Classification System (GMFCS) is a five-level classification system that describes the functional mobilities of children and adolescents with CP [9]. Level I has the fewest limitations and level V has the greatest. The GMFCS offers an indication of the severity of the condition. This book is relevant to those at GMFCS levels I–III: people who are capable of walking independently or with a handheld mobility device. GMFCS levels I–III account for the majority

¹² Both sides of the body are affected.

of children, adolescents, and adults with spastic diplegia. Because self-mobility is limited in spastic diplegia, GMFCS levels IV and V, these levels are best addressed in the book *Children and Youth with Complex Cerebral Palsy* [10].

At GMFCS levels I–III, the descriptors “spastic diplegia” and “bilateral spastic CP” are largely interchangeable. For simplicity, I use just one descriptor for the condition in the text. Because “spastic diplegia” is the descriptor with which I was familiar, and because of its continued use in the US, I have chosen to use it throughout this text. This book equally applies to people with bilateral spastic CP (or simply bilateral CP), GMFCS levels I–III. Indeed, while this book focuses on spastic diplegia, much of what is addressed also applies to other forms of spastic CP at GMFCS levels I–III (hemiplegia and spastic quadriplegia).¹³

Problems with bones, muscles, and joints (musculoskeletal problems) and with walking are generally the most significant issues one encounters in spastic diplegia, GMFCS levels I–III. Because of this, the development and management of musculoskeletal and mobility problems are the main focus of this book. However, children may have problems in other areas, such as with communication or with using their hands. These problems are beyond the scope of this book.

How to read this book

Though each chapter can be read independently, many build on information presented in previous chapters. It is best to first read the book in its entirety to get an overall sense of the condition; after that, you can ignore chapters that are not currently relevant and revisit them only if they become pertinent. Throughout the book, medical/scientific information is interspersed with personal experience. Orange-colored boxes are used to separate personal experience from the other information. In addition, Chapter 5 is devoted to the experiences of people who live with this condition. My son Tommy has written the epilogue. At the back of the book you’ll find a glossary with definitions of key terms you will come across.

¹³ Terms explained in section 1.6.

A companion website for this book is available at www.GilletteChildrensHealthcarePress.org/sdbook. This website contains several resources, including:

- All “Useful web links” throughout the book, collated on one page (helpful for those reading the hardcopy version of the book)¹⁴
- Appendix 7, which is available online only

For simplicity, throughout the book I refer to parents and children; I acknowledge, however, that family structures vary. The term “parent” is used as a generic that includes grandparents, relatives, and carers (caregivers) who are raising a child with spastic diplegia.

Who this book is for

This book is aimed at parents of young children with spastic diplegia as well as adolescents and adults who have the condition. It should also be useful for teachers, extended family members, and students taking undergraduate therapy and other courses (such as special education). It should be helpful for members of multidisciplinary teams because it provides a holistic view of spastic diplegia. A greater understanding of spastic diplegia should help answer many of the questions people have, keep pressure on treatment centers to provide the best evidence-based treatments, and improve quality of life for people who live with this condition.

From reading this book, you will learn that:

- Spastic diplegia arises from an injury to the brain of the developing fetus or infant before two or three years. The brain injury causes problems with movement, and as a consequence, over time, muscle growth and bone development are affected. Intelligence is typically not affected in spastic diplegia.
- There is currently no cure, nor is one imminent.
- People with spastic diplegia have a relatively normal life expectancy.
- The severity of spastic diplegia (i.e., GMFCS level) can be determined by age two. It is not possible to be certain of severity before this age because the baby’s brain is still developing.

¹⁴ All web links were checked at the time of publication, but may change over time. These web links are checked regularly and any changes are noted on this companion website.

- Spastic diplegia is generally mild or moderate, not severe.
- Almost all children with spastic diplegia GMFCS levels I–III walk in childhood.
- A number of treatments are used individually or in combination (e.g., therapies, home program, orthoses,¹⁵ and tone¹⁶ reduction). These treatments are used to increase stretching (to stimulate muscle growth) and to facilitate the development of mobility. The aim is to prevent or delay the onset of muscle and bone abnormalities. The muscle and bone abnormalities that may develop may be addressed with orthopedic surgery.
- Disability can increase with age, and aging can occur earlier than normal in those with spastic diplegia. Good management in childhood and adolescence can optimize outcomes in adulthood.
- Though spastic diplegia affects muscle and bone development and mobility, people with spastic diplegia are able to compete in a variety of sports. Indeed, Paralympians are proof that spastic diplegia does not have to be a barrier to achieving great levels of fitness and skill.
- In the chapter on adulthood, you will read about studies which determined the percentage of adults with CP who, for example, had chronic pain, experienced a decline in walking, or were unemployed. There is much you can do to ensure that you or your child will be among those adults with CP who do not have chronic pain, do not experience a decline in walking, and who are employed.
- There is much that the parent, adolescent, or adult can do to control how much spastic diplegia affects their lives.

¹⁵ An orthosis (or brace) is a device designed to hold specific body parts in position in order to modify their structure and function. It is usually made of lightweight, custom-molded plastic or carbon fiber.

¹⁶ Muscle tone is the resting tension in a person's muscles. A range of "normal" muscle tone exists. Tone is considered "abnormal" when it falls outside the range of normal or typical. It can be too low (hypotonia) or too high (hypertonia).

CHAPTER 1

Cerebral Palsy (CP)

Introduction

*So be sure when you step.
Step with care and great tact
and remember that Life's
a Great Balancing Act [...]
And will you succeed?
Yes! You will, indeed!
(98 and $\frac{3}{4}$ percent guaranteed.)
Kid, you'll move mountains!*

Dr. Seuss, from *Oh, the Places You'll Go!*

To fully understand spastic diplegia, it is worth first having an understanding of the “umbrella term” cerebral palsy (CP). CP was first described in 1861 by an English doctor, William Little, and for many years it was known as “Little’s disease.” Over the years there has been much discussion of the definition of CP, and different definitions have been adopted and later discarded. The most recently adopted definition, published in 2007, is as follows:

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances

that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems [1].

Table 1.1.1 explains the terms used in this definition.

Table 1.1.1 Explanation of terms in definition of CP

TERMS	EXPLANATION
Cerebral	Referring to the cerebrum, the front and upper part of the brain, one of the major areas responsible for the control of movement.
Palsy	<i>Palsy</i> means paralysis, though paralysis by pure definition is not a feature of CP.
Group	CP is not a single condition, unlike conditions such as type 1 diabetes. Rather, CP is a <i>group</i> of conditions. The location, timing, and type of brain injury vary, and the resulting effects of the brain injury are also varied. A simple blood test for glucose confirms a diagnosis of type 1 diabetes. A genetic test confirms Down syndrome. Unfortunately, there is no equivalent single test for CP.
Permanent	Refers to the fact that the brain injury remains for life: CP is a lifelong condition.
Disorders	A <i>disorder</i> is a disruption in the usual orderly process. To meet the definition of CP, the disorder must cause activity limitation.
Posture	The way a person holds their body when standing or sitting.
Activity limitation	<i>Activity</i> is the execution of a task or action by an individual. <i>Activity limitations</i> are difficulties an individual may have in executing activities. Walking with difficulty is an example of an activity limitation.
Non-progressive	The brain injury does not worsen, but its effects can develop/evolve over time.
Developing fetal or infant brain	The brain injury occurs in an immature, rather than a mature, brain. An injury to the <i>fetal or infant brain</i> happens before the brain is finished developing all of its neural connections.

TERMS	EXPLANATION
Motor disorders	<i>Motor disorders</i> are conditions affecting the development of movement and posture. The term <i>motor impairment</i> can also be used.
Are often accompanied by	The motor problem is often associated with other problems.
Sensation, perception, cognition, communication, and behavior	<i>Sensation</i> : Refers to the senses; i.e., vision, hearing, and others. <i>Perception</i> : The ability to incorporate and interpret sensory and/or cognitive information. <i>Cognition</i> : The mental action or process of acquiring knowledge and understanding through thought, experience, and the senses. <i>Communication</i> : The imparting or exchanging of information. <i>Behavior</i> : The way one acts or conducts oneself.
Epilepsy	<i>Epilepsy</i> is a seizure disorder. A seizure is an abnormal electrical discharge in brain cells that disrupts normal activity, behavior, or movement. Seizures can vary in length and severity.
Secondary musculoskeletal problems	<i>Musculoskeletal</i> refers to both the muscles and the skeleton; i.e., the muscles, bones, and joints. <i>Musculoskeletal problems</i> appear with time and growth, hence they are termed <i>secondary problems</i> or <i>abnormalities</i> . They develop as a consequence of the brain injury. People with CP may develop a variety of musculoskeletal problems, such as muscle/tendon contracture or bone torsion (twist).

Adapted from Rosenbaum et al. (2007).

CP is a lifelong condition. There is currently no cure [2], nor is one imminent, but good management and treatment (addressed in Chapter 3) can help alleviate some or many of the effects of the brain injury.

When the brain injury occurs is important. The consequences of a brain injury to a fetus developing in the womb are generally different from those of a brain injury sustained at birth, which in turn are different from those of a brain injury acquired during infancy. It is generally

accepted that only brain injuries occurring before the age of two or three fit the definition of CP [1]. A brain injury occurring after that age is called an acquired brain injury. This cutoff is due to the differences in brain maturity when the injury occurs.

This chapter contains background information on CP. It covers:

Section 1.2 Causes, risk factors, and prevalence

Section 1.3 Diagnosis

Section 1.4 The International Classification of Functioning, Disability and Health (ICF)

Section 1.5 Motor function, gross motor milestones

Section 1.6 Classification of CP

The term “cerebral palsy” first came into our lives when Tommy was about one year old. Until then it was a term I was vaguely familiar with but could not have explained.

Tommy missed developmental milestones and was initially described as “developmentally delayed.” Months passed, but no diagnosis was forthcoming. By his first birthday he was unable to sit without support or even hold a bottle. I decided to seek a second opinion from a pediatrician known to be a straight talker. On the day of the appointment, I collected our two older children from school. They remained in the waiting room, happy with the promise of a visit to the McDonald’s next door after the appointment.

After the usual brief introductory pleasantries, the pediatrician examined Tommy. The conversation that followed went something like this:

Pediatrician: Do you not know what’s wrong with this child?

Me: (*Politely*) No. (*Thinking*: If I did, I wouldn’t be here.)

Pediatrician: (*Matter-of-fact*) He has cerebral palsy. And what’s more, if I want to know how this child will turn out, I don’t look at the child, I look at the mother.

Though this was certainly not what I had expected, nor what I wanted to hear, I felt a strange sense of relief after the months of uncertainty and worry. I appreciated knowing, and I appreciated the doctor's straight-talking manner.

That day, three lively children and one dazed mother visited McDonald's. That day, I had no opinion on the matter, but 25 years later I definitely agree with the pediatrician: we parents are key influencers of outcome. That day, having received Tommy's diagnosis, I wish I could have been given this book.

Useful web links

- Cerebral Palsy Alliance (2014) *What Is Cerebral Palsy?* [video] youtube.com/watch?v=Rsk3VQ-gr34
- Cerebral Palsy Foundation (2016) *What Is Cerebral Palsy?* [video] youtube.com/watch?v=8XH0WPasBzQ
- Ontario Brain Institute (2017) *Meet Jessica. This Is What She Wants You to Know about Cerebral Palsy.* [video] youtu.be/MSd3LwwJksU
- CP Now (2015) *The Cerebral Palsy Toolkit: From Diagnosis to Understanding.* [pdf] cpnowfoundation.org/wp/wp-content/uploads/2015/11/CP-ToolKit.pdf
- UK National Institute for Health and Care Excellence (NICE) (2017) *Cerebral Palsy in Under 25s: Assessment and Management.* [online] nice.org.uk/guidance/ng62
- Gillette Children's Specialty Healthcare (2016) *Cerebral Palsy Road Map: What to Expect as Your Child Grows.* [pdf] gillettechildrens.org/assets/uploads/care-and-conditions/CP_Roadmap.pdf (The road map covers all types of CP and all GMFCS levels. It is organized into four age groups from birth to age 18. It covers 10 areas of interest including mobility, musculoskeletal, and interventions.)

1.2

Causes, risk factors, and prevalence

*The little reed, bending to the force of the wind,
soon stood upright again when the storm had passed over.*

Aesop

Causes and risk factors

The term “cause” is self-explanatory. The term “risk factor” can be defined as “any attribute, characteristic, or exposure of an individual that increases the likelihood of developing a disease or injury” [1]. Causes thus have a stronger relationship with CP than risk factors. Significant deprivation of oxygen to the infant’s brain, for example, is a cause of CP. Preterm birth is a risk factor but not a cause of CP—in other words, not every preterm baby is found to have CP. There are many possible causes of brain injury, including events before and during pregnancy, during birth, or in early infant life. Much is known about the causes and risk factors for CP, but much remains unknown as well. Depending on what you read, you may come across different lists of causes and risk factors for CP. The following are from the Gillette website [2].

a) Causes of CP

Developing fetuses and infants (up to age two to three) can develop CP if they experience brain injury or disruptions in brain development caused by:

- Bleeding in the brain before, during, or after birth
- Infections of the brain, including meningitis or encephalitis¹⁷
- Shock—a state in which organs and tissues do not receive adequate blood flow
- Traumatic brain injuries, such as from a serious car accident
- Seizures at birth or in the first month following birth
- Certain genetic conditions

b) Risk factors for CP

Risk factors for CP include:

- Preterm birth and low birth weight. A typical pregnancy lasts 40 weeks. Babies born before 37 weeks have a greater risk of having CP. The risk increases the earlier a baby is born and the lower the baby's birth weight. Twins and other multiple-birth siblings are at particular risk because they tend to be born earlier and at lower birth weights.
- Serious illness, stroke, or infection in the mother. CP is more common in children whose mothers:
 - Experience certain viral and bacterial infections and/or high fevers during pregnancy.
 - Have coagulation (clotting) disorders or experience blood clots during pregnancy.
 - Receive excessive exposure to harmful substances during pregnancy.
 - Have thyroid problems, seizure disorders, or other serious health concerns.
- Serious illness, stroke, or infection in the baby. Infants who experience serious illnesses, strokes, or seizures around the time of birth are at greater risk of having CP. Such illnesses might include:
 - Severe jaundice. (Kernicterus is a rare kind of preventable brain damage that can happen in newborns with jaundice.)
 - Seizures during the first 48 hours after birth.

¹⁷ Encephalitis is an acute inflammation (swelling) of the brain, normally resulting from a viral infection or the immune system mistakenly attacking the brain tissue.

- Infections of the brain, such as meningitis or encephalitis.
- Strokes caused by broken or clogged blood vessels or abnormal blood cells.
- Pregnancy and birth complications. For example, not enough nutrition through the placenta or a lack of oxygen during labor and birth. Incompatible blood types between mother and baby.
- Genetic issues.

c) What the literature tells us

- Although any one risk factor, if severe, may be sufficient to cause CP, more often it is the presence of multiple risk factors that leads to CP. One factor may interact with another to cause the brain injury, such as an event (or events) during pregnancy combined with the stress of birth combined with a genetic vulnerability [3].
- The literature suggests that events during pregnancy are more likely to cause CP than events during labor or delivery. More specifically:
 - A major US study, called the Collaborative Perinatal Project, conducted between 1959 and 1974 followed approximately 50,000 women and their children from the first prenatal visit until the children were seven years old. It found that events during labor and delivery were not major contributors to the occurrence of CP; most cases had their origins before labor began. A second finding was that intrauterine inflammation¹⁸ was a major cause of adverse pregnancy outcome [4].
 - At least 70 percent of cases of CP have antecedents¹⁹ during pregnancy, and only 10 to 20 percent of cases are related to the child's birth [5]. Neither the routine use of fetal monitoring during labor nor the increased incidence of caesarean births (factors which reduce risk during labor and delivery) have reduced the number of cases of CP [5].
 - Most brain injuries which cause CP occur in the second half of pregnancy, a period when the rate of brain development is fastest [6].

¹⁸ Inflammation occurs when part of the body becomes reddened, swollen, hot, and often painful, especially as a reaction to injury or infection.

¹⁹ Things that existed before or that logically preceded another event.

- Some risk factors are on the decline, but others are increasing [5,7]. Advances in neonatal care have reduced the risk of birth injury. However, with these advances more preterm infants and infants with low birth weight are surviving, some of whom may develop CP. In vitro fertilization has led to more multiple births, and multiple births, as noted above, is a risk factor for CP. The fact that some risk factors are decreasing while others are increasing is leading to a change in the type of CP that develops. For example, an injury to a brain at 24 weeks can have a different effect than one at 28 weeks or 36 weeks. Until recently, babies born at 24 weeks would not have survived. Now, thankfully, many of these babies survive; however, some may develop CP. The most common types of CP differ in different parts of the world, depending on risk factors.
- In approximately 90 percent of cases, CP results from healthy brain tissue becoming damaged rather than from abnormalities in brain development [7].
- Confirmation of the presence of a brain injury by magnetic resonance imaging (MRI) occurs in many but not all cases. Up to 17 percent of people with CP have normal MRI brain scans [7]. Imaging may also help determine when the brain injury occurred [7].
- The cause of CP in an individual child is very often unknown [8].

We don't know what caused Tommy's CP, but that is not unusual. Like many other parents, I would like to have known.

Prevalence

The prevalence of a condition is how many people in a defined population have the condition at a specific point in time. Prevalence rates can vary geographically. A 2013 worldwide review found that the overall prevalence of CP was 2.11 per 1,000 live births [9].²⁰ It also found that the prevalence of CP has remained constant despite increased survival of at-risk preterm infants. A recent (2019) study, however, reported that the birth prevalence²¹ of CP declined across Australian states between

²⁰ Births up to 2004.

²¹ This was formerly referred to as “incidence,” but the term “birth prevalence” is now felt to be more accurate [10].

1995 and 2009 [10]. The percentage of children with CP whose disability was moderate to severe also decreased. This is encouraging.

Some further points:

- CP is the most common cause of physical disability in children [7].
- Males are at higher risk of CP than females. Recent data from Australia found that 57 percent of those with CP were male, while males represented 51 percent of all births [11]. This may be because males have certain nerve cell vulnerabilities that may result in CP [5]. It is noteworthy that there are frequently more male than female participants in CP studies.
- Relative to its prevalence and its impact on the life span of those with the condition, funding for CP research is very low. The National Institutes of Health (NIH) is the primary US body responsible for health research; it reports research funding by condition. Although the reported prevalence of CP was three times higher than that of Down syndrome (0.3 percent versus 0.1 percent), funding allocated to CP research in 2018 (\$26 million) was significantly lower than that allocated to Down syndrome research (\$60 million) [12]. Funding estimates for 2019 and 2020 are \$28 and \$24 million, respectively, for CP and \$72 and \$65 million for Down syndrome.

I believe it would be beneficial if, once a child is diagnosed with CP (up to three years after birth), there were some way of conveying this diagnosis to the obstetrician who provided care to the mother and infant during pregnancy and birth. This information may inform future practice. Or parents could consider giving consent to have their child added to a properly governed regional or national CP register and allowing appropriate access to medical records from pregnancy and birth.

Though I did not know what caused Tommy's CP, in the early days I wasted a lot of time feeling guilty. I had worked very hard and was stressed during his pregnancy, and I felt responsible. Today I no longer feel that sense of guilt. I didn't knowingly do anything wrong: my life circumstances were such that I was very busy, and besides, there are multiple possible causes of brain injury. I encourage parents to waste no time on guilt—we are where we are and we must move forward.

1.3

Diagnosis

*Acceptance is knowing that grief is a raging river.
And you have to get into it.
Because when you do, it carries you to the next place.
It eventually takes you to open land,
somewhere where it will turn out OK in the end.*

Simone George

Sometimes it is obvious from birth that a new baby has CP, but in many cases it is not. The possibility may be anticipated because of problems in pregnancy or a preterm or difficult birth, or the suspicion may only arise when developmental milestones are missed. Even if a professional is suspicious of CP, that suspicion may not be communicated to parents. Unfortunately, unlike with other conditions, such as Down syndrome, there is no definitive test for CP.

The difficulty of diagnosing CP arises more in the mild and moderate forms of the condition since the severe forms are generally apparent early on. The majority of spastic diplegia is mild or moderate, thus the difficulty of diagnosis is a very real issue. However, there seems to be a recent shift toward earlier diagnosis:

- McIntyre and colleagues (2011) proposed a change from referring an infant for intervention following a formal—most often late—diagnosis of CP to doing so as soon as the infant is considered “at risk” of CP. (Their paper was titled “Cerebral Palsy—Don’t Delay.” [1])
- Graham and colleagues (2016) noted that any infant with known risk factors should be considered at risk and enhanced screening should be offered [2].
- A number of assessments can be used for diagnosis before five months corrected age,²² including MRI, Prechtl’s General Movements Assessment, Test of Infant Motor Performance (TIMP),²³ and a standardized neurological examination [3,4].

Novak and colleagues (2017) noted that clinicians²⁴ should understand the importance of prompt referral to diagnostic-specific early intervention in order to [4]:

- Optimize infant motor and cognitive plasticity²⁵
- Prevent secondary musculoskeletal problems
- Support the parents after they have received the diagnosis

Parents’ chief criticisms of medical professionals responsible for diagnosis relate to unclear information and communication of a pessimistic outlook [5].

Diagnosis has been described as a process, not an event [6]. There’s only so much parents can absorb in the first meeting, so subsequent follow-up is needed.

²² With preterm babies, it takes time to determine whether the delays are related to being preterm or are true delays. The term “corrected age” refers to how old a baby would be if they had been born on their due date rather than preterm. “Chronological age” refers to how old a baby is from their date of birth. Corrected age is often used when assessing growth and developmental skills.

²³ Prechtl’s General Movements Assessment and Test of Infant Motor Performance (TIMP) are assessments of infant movement.

²⁴ Clinicians are medical professionals who have direct contact with patients rather than being involved with, for example, research or laboratory work.

²⁵ “Cognition” may be defined as the process of acquiring knowledge and understanding. Motor and cognitive plasticity are types of neuroplasticity. “Plasticity” refers to the ability of the human brain to recover after an injury through the ability of nerve cells to alter their structure and function in response to a variety of external and internal pressures, including behavioral training [7].

Receiving the news that your beautiful child has CP is very tough for parents, who may then go through a grieving process. Looking back, I found that the diagnosis was almost a help after all the months of uncertainty. It galvanized me into immediate action to find out how I could best help my child. This was probably my way of coping with the news. Every parent will deal with the diagnosis in their own way, but I would encourage all parents to try to get as good an understanding of the condition as they can, as soon as they can. To that end this book may be helpful.

One of the early readers of this book, a nurse and psychotherapist who has a son with spastic diplegia, wrote a piece about the different stages of dealing with a diagnosis. I've included it in Appendix 1.

Looking back at photographs from Tommy's first year, I can now see that the signs of his CP were obvious from very early on. In retrospect, I feel his diagnosis could have been made much earlier. Because he wasn't diagnosed until he was a year old, intervention only started in earnest then. If a clinician suspects a child of having CP, I believe they should communicate this to the parents immediately. The possible harm done by delaying diagnosis, and therefore intervention, is to my mind greater than the possible harm done by raising a suspicion that later proves unwarranted. The only intervention the child is likely to receive during that period is physical therapy, which won't do them any harm.

You may ask, why would a diagnosis be delayed? One reason is that a physician might not want to give parents this significant diagnosis until they are very sure that it is accurate.

What should a medical professional who is not responsible for diagnosis do if they strongly suspects a child in their care has CP? In my view, such a professional has a responsibility to communicate, without delay, with the person responsible for diagnosis. Likewise, if parents have any suspicion that their child may have a problem, they should communicate it to their physician as soon as possible.

I remember discussing diagnosis with a friend who made an interesting point: sometimes the parent would rather not hear bad news; having one foot out the door, so to speak, may be easiest for both the physician

and the parent. But this doesn't make sense—it just prolongs the anxiety and delays intervention while the clock is ticking.

I was happy to read in the literature about the recent shift toward earlier diagnosis. I was also heartened to read a paper by Graham and colleagues (2016) noting that mothers of children with CP who have previously had a typically developing child often sense that something is wrong at a very early stage [8]. This paper advised professionals to take the concerns of an experienced parent seriously. I sensed that something was wrong when Tommy was just a day old. He cried so incessantly that by evening I asked if he could be checked by a pediatrician. I did not feel all was fine; his prolonged crying had an unusual pitch. The on-duty pediatrician came to see him and reassured me that all was well, and I accepted her reassurance. Years later, I remember gently suggesting to a close friend that she have her baby assessed because I felt he had a very unusual cry. My friend's baby turned out to have a significant developmental problem.

When Tommy was very young, I read a short essay titled “Welcome to Holland.” It was written in 1987 by Emily Perl Kingsley, a writer on the TV series *Sesame Street*, about parenting her son, who was born with Down syndrome. She described it as going on vacation, but not to the expected destination. Though some people may find it overly sentimental, the essay resonates with me to this day. I've included a web link to it at the end of this section.

Useful web links

- Cerebral Palsy Alliance (2018) *Precht's General Movements Assessment*. [pdf] cerebralpalsy.org.au/wp-content/uploads/2018/03/Parental-Fact-Sheets.pdf
- National Down Syndrome Society (1987) “A Parent's Perspective: Welcome to Holland by Emily Perl Kingsley.” [online] ndss.org/resources/a-parents-perspective/
- CP-NET (2015) *Creating Possibilities for Cerebral Palsy*. [video] vimeo.com/141592022

1.4

The International Classification of Functioning, Disability and Health (ICF)

*The individual is rarely going to be altered very much,
whereas the environment slowly but surely can.*

Tom Shakespeare

The World Health Organization (WHO)²⁶ developed a framework for considering any health condition called the International Classification of Functioning, Disability and Health [1]. The framework²⁷ helps show the impact of a health condition at different levels and how those levels are interconnected. It reminds us to look at the full picture—to look at the person with a disability in the context of their world. The framework’s long title is abbreviated to ICF; the F stands for Functioning, which shows where its emphasis lies.

The framework gives us a way of looking at the concepts of health and disability. It acknowledges that every human being can experience

²⁶ The World Health Organization (WHO) is the agency of the United Nations concerned with public health. In 1948, the year it was established, the WHO adopted the following definition of health: “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” This is a very interesting and broad definition. It is also interesting that this 1948 definition has not been amended—it has stood the test of time.

²⁷ A framework is a structure to explain a particular concept.

a decrease in health and thereby experience some disability. It is not something that happens only to a minority of people. The ICF thus “mainstreams” disability and recognizes it as a widespread human experience. By shifting the focus from the *cause* to the *impact* of a health condition, the ICF places all health conditions on an equal footing, allowing them to be compared [2].

You might wonder why we need a framework to understand a health condition. As I became more familiar with the ICF, I could really see its usefulness. The idea that every human being can experience a decrease in health and therefore experience some disability is useful because it illustrates that people don't fit neatly into one of two boxes (metaphorically speaking), healthy or disabled. There is, rather, a continuum between health and disability. The framework is helpful because it focuses on how a person with CP functions in their life.

See Figure 1.4.1.

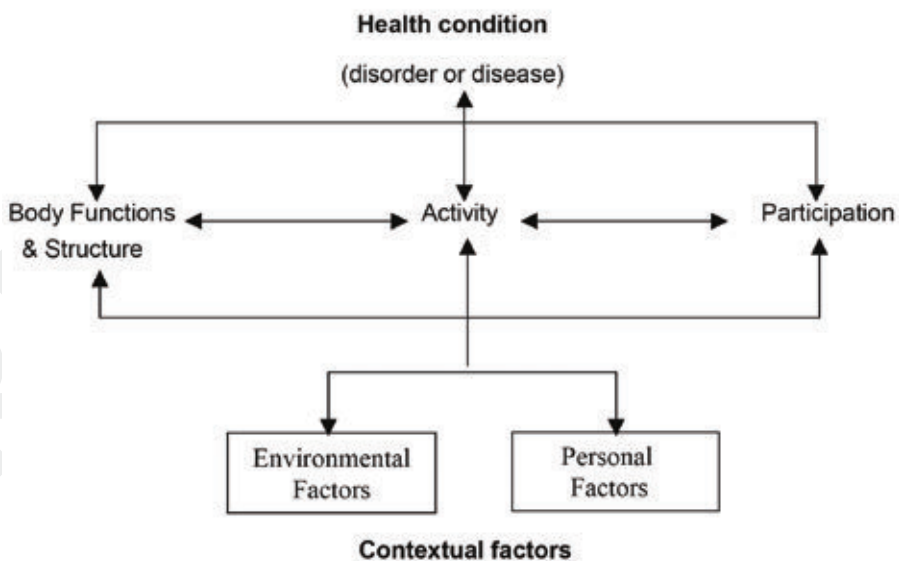


Figure 1.4.1 International Classification of Functioning, Disability and Health (ICF). Reproduced with kind permission from WHO.

The framework describes three levels of human functioning and characterizes disability as difficulty functioning at one or more of these three levels [1,2]:

- **Body functions and structure** refers to functioning at the level of the body or a body part.²⁸ Spasticity is at this level. **Impairments** are problems in body function or structure, such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual. Is the person able to walk or kick a ball? **Activity limitations** are difficulties an individual may have in executing activities. To meet the latest (2007) definition of CP, a permanent motor disorder has to cause activity limitation [3].
- **Participation** is involvement in a life situation. Being able to play sports with friends or having a job are examples of participating in society. **Participation restrictions** are problems an individual may experience with their involvement in life situations.

The framework also includes factors that influence any of the three levels of functioning (termed contextual factors):

- **Environmental factors** make up the physical, social, and attitudinal environment in which people live and conduct their lives [2]. Examples of physical environment include structural barriers at home and in the community, such as steps or stairs without handrails in the house, or a school building with stairs but no elevator.
- **Personal factors** include gender, age, coping style, social background, education, profession, past and present experiences, and other factors that influence how disability is experienced by the person [2]. Examples of personal factors include a person's attitude, determination, motivation, and perseverance.

The three levels of human functioning, plus environmental and personal factors, are all interconnected with the health condition.

With regard to activity, the ICF distinguishes between **motor capacity**—what a person can do in a standardized, controlled environment, and **motor performance**—what a person actually does in their daily

²⁸ The WHO formally defines “body functions” as physiological functions of body systems (including psychological functions). “Body structures” are defined as anatomical parts of the body such as organs, limbs, and their components [2].

environment. For example: is the child walking at an appointment on a smooth surface with the medical professional and parent watching and encouraging them the same as their walking in a crowded playground on possibly uneven surfaces?

There is a third concept to keep in mind when considering activity: **motor capability**—what a person can do in their daily environment [4]. For example, a child may be able to ride a bike to school—they have the capability—but they may choose not to. Their performance is influenced by their choice. Holsbeeke and colleagues (2009) noted that physical and social environment and personal factors such as motivation influence the relationship between capacity, capability, and performance.

A series of “F-words” have been developed and inserted into the different areas of the ICF, providing a useful adaptation of the framework [5]. See Figure 1.4.2. The authors highlighted **fitness, function, friends, family, fun, and future** as areas of focus for the child with a health condition. Indeed, these also apply to adults. Web links to a number of useful videos on the F-words are included at the end of this section.

I’ve observed how becoming familiar with the ICF has influenced my thinking over the years. In the early days, I was very focused on issues at the level of body functions and structure. Later I came to understand the relationship between the three levels. For example, orthopedic surgery leads to improvements at the level of body functions and structure by addressing muscle and bone problems. As a result, the child may walk more easily and their walking might consume less energy. This is an improvement at the activity level. If walking is less tiring, the child might be able to keep up and do more with their peers—an improvement at the participation level. I also came to understand that treatments need to benefit a child at the level of activity and/or participation rather than purely at the level of body functions and structure. It is important to keep in mind that one cannot assume that a treatment at one level will necessarily help the child at another [6].

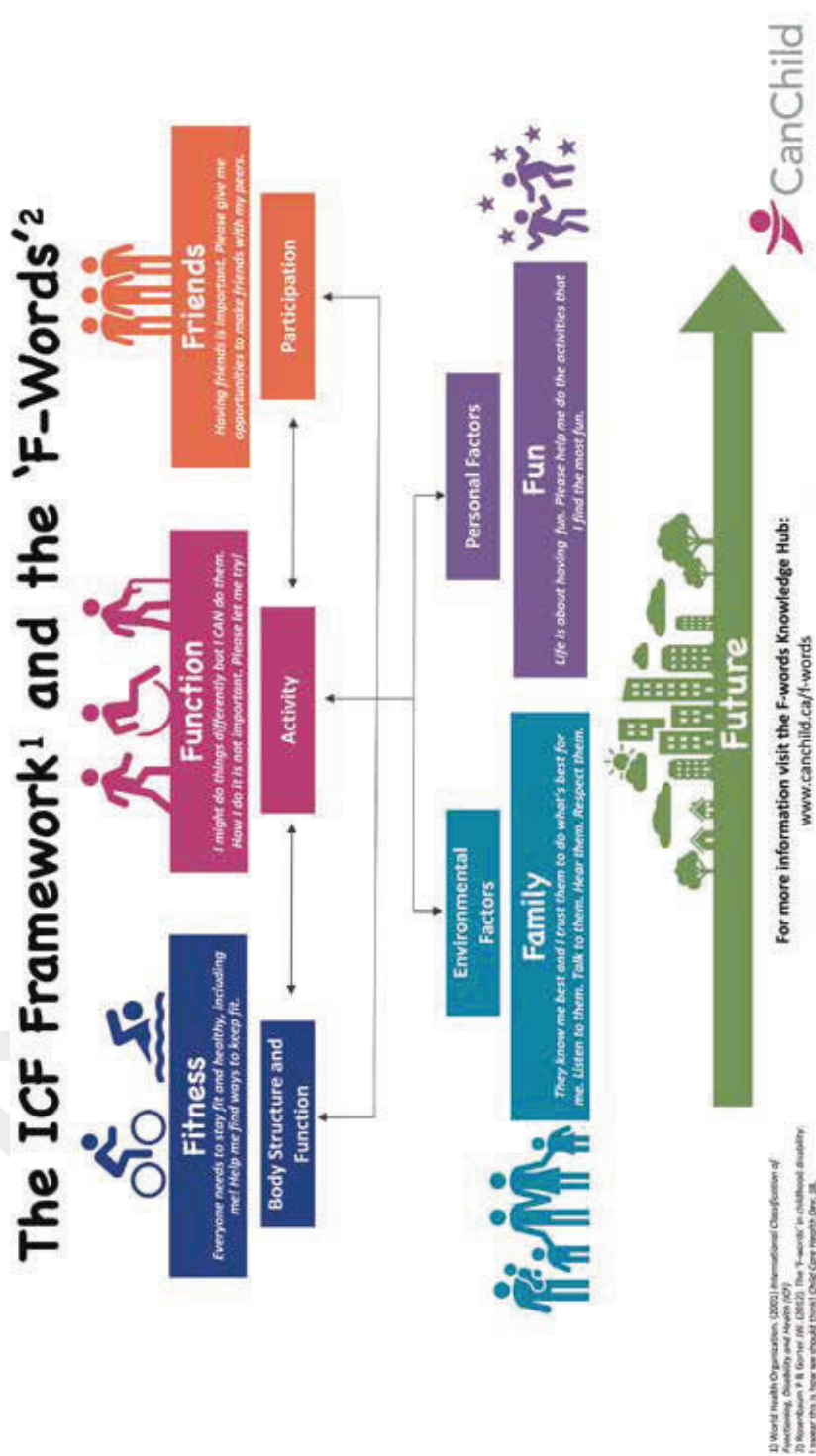


Figure 1.4.2 The ICF framework (WHO 2001) and the F-words (Rosenbaum and Gorter 2012).
Reproduced with kind permission from CanChild.

Useful web links

- CanChild (2019) *The ICF for Parents (P-ICF)*. [online] canchild.ca/en/the-icf-for-parents-p-icf (Scroll down the page for a very useful video series on the ICF.)
- Cerebral Palsy Foundation (2016) *The F Words of Disability*. [video] youtu.be/tFeV166kuUY
- CP-NET (2018) *My Favourite Words*. [video] vimeo.com/252166407
- CP-NET (2015) *These Six F-Words Won't Fill up Your Swear Jar: What Do the F-Words Mean to Youth with Impairments?* [video] vimeo.com/236235559

1.5

Motor function, gross motor milestones

*That's one small step for man,
one giant leap for mankind.*

Neil Armstrong

Motor function

Motor function is divided into two types: gross motor function and fine motor function.

- **Gross motor function** (or **gross motor skills** or **gross motor activities**) refers to the movement of the arms, legs, and other large body parts. It involves the use of large muscles. Examples include sitting, crawling, standing, running, jumping, swimming, throwing, catching, and kicking. These movements involve maintaining balance and changing position.
- **Fine motor function** (or **fine motor skills** or **fine motor activities**) refers to smaller movements that occur in the wrists, hands, fingers, feet, and toes. It involves the control of small muscles. Examples include picking up objects between the thumb and forefinger, and writing. These movements typically involve hand-eye coordination and require a high degree of precision of hand and finger movement.

The development of gross and fine motor skills is under neurological control (i.e., under the control of the nervous system) and is affected to varying degrees in CP. Gross and fine motor function may improve somewhat without treatment, but treatment is essential to maximize the individual's motor function as early as possible, which is why early intervention is so important.

Gross motor milestones

There is a usual sequence and timing to the achievement of gross motor milestones in the typically developing child. A large study conducted by the WHO found that, with some variation, almost all typically developing children have achieved independent sitting by nine months and independent walking by 18 months [1].²⁹ The average age and age range for achieving each of the six gross motor milestones are as follows:

- Sitting without support 6.0 (3.8–9.2) months
- Standing with assistance 7.6 (4.8–11.4) months
- Hands and knees crawling 8.5 (5.2–13.5) months
- Walking with assistance 9.2 (5.9–13.7) months
- Standing alone 11.0 (6.9–16.9) months
- Walking alone 12.1 (8.2–17.6) months

These milestones are an important reference when a child appears to be late in development compared with typically developing children. One of the hallmarks of CP is that the child may be late achieving gross motor milestones. In fact, that may be what first alerts parents and/or professionals to a problem. It is also worth noting that not all children crawl (even typically developing children).

The earlier motor development stages—sitting, standing, crawling—are important for the development of walking. Earlier developmental stages include the precursors of later ones. To the extent possible, following (going through) these motor development stages is important for the child with CP. However, there is a balance to be achieved. For example, research has shown that providing powered mobility to children as young as 2.5 years of age who have more severe motor disabilities is beneficial in terms of function and development [2,3]. With powered

²⁹ The study collected data from 816 healthy children over multiple years in different regions and is representative of children worldwide. The study found no difference between boys and girls.

mobility the children's language, exploration, social function, and efforts at self-initiated movement showed improvement. Even for children with less severe motor disability, there may be a balance between following normal motor development stages and promoting the child's activity and participation.

A web link to the WHO gross motor milestones is included at the end of this section. A web link to the developmental milestones published by the US Centers for Disease Control and Prevention (CDC)³⁰ is also included. In addition to movement and physical development, the CDC's information sheet includes social/emotional, language/communication, and cognitive (learning, thinking, and problem-solving) development for children up to five years of age.

Measuring gross motor function

One commonly used method for measuring gross motor function in CP is the Gross Motor Function Measure (GMFM) [4]. The GMFM-88 consists of 88 items (skills) that measure a child's abilities in five areas of increasing gross motor function:

- Lying and rolling
- Sitting
- Crawling and kneeling
- Standing
- Walking, running, and jumping

The 88 items are skills that are well established in typically developing children by the age of five. A web link to the full 88 GMFM items is included at the end of this section. It is worth consulting because it gives you an idea of the skills that exist beyond independent walking (item 69 on the GMFM). They include stepping over obstacles, kicking a ball, running, jumping, and stair climbing. These skills involve balance. The assessment is completed (usually by a physical therapist) with the child in bare feet—that is, without walking aids, orthoses, or shoes. (The assistance these supports provide can be checked by repeating the assessment with them. A child may be able to walk with orthoses, shoes,

³⁰ The Centers for Disease Control and Prevention (CDC) is the leading national public health institute in the US.

and crutches for support, for example, but not without them.) Most children with even mild CP fail to complete all items.³¹

The results for each item are then totaled and expressed as a percentage of the maximum possible score. The higher a child's gross motor function, the higher their GMFM-88 score. There is also a shorter, 66-item version called the GMFM-66 [5]. The GMFM-66 requires software to compute the result.³² It is scored 0–100.

In relation to the ICF, the GMFM measures skills at the activity level. GMFM is a measure of what the child can do, not how well they do it. For example, item 69 tests whether the child can walk forward 10 steps, not how well they walk that distance. (In addition, as noted above, the child may not be able to walk the distance in bare feet but may be able to walk it with an aid, such as crutches.)

Further information on gross motor function is included in Appendix 2.

As a parent, I never thought too much about walking. My two older children walked before their first birthdays and developed running and jumping skills without my ever having to notice or think about them. It is only when there is a problem that we begin to think about what walking actually involves.

The reason I include so much information on gross motor function in this section is to ensure that readers understand what it means to improve gross motor function. It's about more than merely achieving the gross motor milestones: a small increase in gross motor function, as measured by the GMFM, can have a big effect on the child's life.

³¹ Gross motor function is not exclusively measured by the GMFM. There are a number of tools that are used to screen for developmental motor delays in addition to motor function depending on the age of the child. They include Test of Infant Motor Performance, Bayley Scales of Infant and Toddler Development, Peabody Development Motor Scales, and Bruininks Oseretsky Test of Motor Proficiency.

³² In the GMFM-66 items are graded by difficulty, whereas in the GMFM-88 all items contribute equally to the overall result regardless of difficulty.

Useful web links

- CanChild (2013) *GMFM Score Sheet*. [pdf] canchild.ca/system/tenon/assets/attachments/000/000/218/original/gmfm-88_and_66_scoresheet.pdf
- WHO (2019) *Motor Development Milestones*. [online] who.int/childgrowth/standards/motor_milestones/en/
- CDC (2019) *CDC's Developmental Milestones*. [online] cdc.gov/ncbddd/actearly/milestones/index.html
- Healthy Children (2019) *Does My Child Have Physical Developmental Delays?* [online] healthychildren.org/English/MotorDelay/Pages/default.aspx#/ (Healthy Children is a website of the American Academy of Pediatrics.)

1.6

Classification of CP

Order and simplification are the first steps toward the mastery of a subject. The actual enemy is the unknown.

Thomas Mann, from *The Magic Mountain*

Classification of CP

Over the years, there has been much discussion of the classification of CP. Classification, or dividing into groups, is useful for a number of reasons. First, it provides information about the nature of the condition and its severity (its level or magnitude). Second, it allows us to learn from people who have the condition at a similar level.

A good measurement or classification system must be:

- **Valid:** It actually measures what it claims to measure.
- **Reliable:** It provides the same answer when used by different people or by the same person at different times.
- **Accurate:** It measures how close a value is to its true value. (An example would be how close an arrow gets to the target.)
- **Precise:** It measures how repeatable a measurement is. (An example

would be how close the second arrow is to the first one, regardless of whether either is near the target.)

A kitchen scale (weighing scales) can be used to illustrate the different concepts:

- If the scale claims to measure weight and does so, then the scale is valid.
- If it provides the same reading regardless of who uses it or when they use it, then the scale is reliable.
- If the reading is correct when a known standard weight is weighed, then the scale is accurate.
- If repeated weighings of the same item give the same reading (whether accurate or not), then the scale is precise.

In this section we cover three main methods of classifying CP. These are based on:

- a) **Topography:** The area of the body affected
- b) **Motor impairment:** The type of motor disorder (a motor disorder affects the development of movement and posture)
- c) **Gross motor function:** The level of functional mobility

a) Classification of CP on the basis of topography

The historical method of classifying CP is on the basis of topography—the area of the body affected [1,2]. The suffix “-plegia” is derived from the Greek word for stroke. The prefixes “mono-,” “hemi-,” “di-,” “tri-,” and “quad-,” again derived from the Greek or Latin words, indicate the area of the body affected. See Table 1.6.1.

One of the disadvantages of this classification system is a lack of precision. However, this method of classifying CP has been and continues to be used extensively, particularly the terms “hemiplegia,” “diplegia,” and “quadriplegia” in the US.

A recently adopted classification system, again based on topography, was adopted by the Surveillance of Cerebral Palsy in Europe (SCPE) group [3]. The SCPE’s classification system is thought to be reasonably

reliable with room for improvement [4]. It is now generally used in Europe and Australia. It identifies two main types of CP: unilateral and bilateral. See Table 1.6.2.

Table 1.6.1 Classification of CP on the basis of topography—historically [1,2]






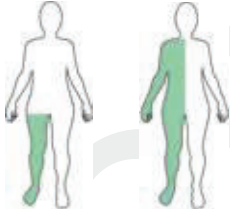
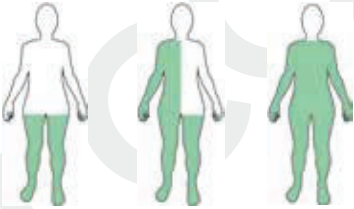
CP SUBTYPE	AREA OF BODY AFFECTED	
Monoplegia	<i>Mono</i> = One Affecting one limb, usually the lower limb.	
Hemiplegia	<i>Hemi</i> = Half Affecting the upper and lower limbs on one side of the body. The upper limb is usually more affected than the lower limb.	
Diplegia	<i>Di</i> = Two Affecting all limbs, but the lower limbs are much more affected than the upper limbs, which frequently only show fine motor impairment.	
Triplegia	<i>Tri</i> = Three Affecting three limbs, usually the two lower limbs and one upper limb. The lower limb is usually more affected on the side of the upper-limb involvement.	
Quadriplegia	<i>Quad</i> = Four Affecting all four limbs and the trunk. This is also known as tetraplegia.	

Table 1.6.2 Classification of CP on the basis of topography—SCPE [3]

CP SUBTYPE	AREA OF BODY AFFECTED	
Unilateral	One side of the body is affected.	
Bilateral	Both sides of the body are affected.	

b) Classification of CP on the basis of motor impairment

Another method classifies CP into subtypes based on the predominant features of the motor impairment.³³ CP is characterized by abnormal muscle tone and problems with motor control which may or may not include involuntary movements. A brief explanation of the subtypes is included in Table 1.6.3.

Most studies report that spasticity is the most common type of motor impairment, though the exact percentage varies. The general consensus is that 60 to 85 percent of those with CP have the spastic form [5]. Only spastic CP is subdivided into bilateral or unilateral [3]. This is because dyskinetic and ataxic CP generally affect the whole body.

A web link to a useful video titled *Types of CP* is included at the end of this section.

³³ A motor impairment or motor disorder is a condition affecting the development of movement and posture.

Table 1.6.3 Classification of CP on the basis of motor impairment

CP SUBTYPE	EXPLANATION
Spastic (spasticity)	<i>Spasticity</i> is a condition in which there is an abnormal increase in muscle tone or stiffness of muscle which might interfere with movement, speech, or be associated with discomfort or pain [6]. Lance (1980) included “a velocity-dependent increase in the stretch reflex” in his definition of spasticity [7]. Spastic CP can be subdivided into <i>unilateral</i> or <i>bilateral</i> based on whether one or two sides of the body are involved [3].
Dyskinetic (dyskinesia)	<p><i>Dyskinetic</i> CP is defined as “abnormal patterns of posture and/or movement associated with involuntary, uncontrolled, recurring, occasionally stereotyped movement patterns” [1]. (<i>Stereotyped movement patterns</i> means the movements are in a particular pattern, specific to that person, which is repeated.) Dyskinetic CP can be subdivided into either <i>dystonic</i> or <i>choreo-athetotic</i> CP [3].</p> <ul style="list-style-type: none"> • Dystonic (dystonia): The dystonias are movement disorders in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures. The movements, which are involuntary and sometimes painful, may affect a single muscle; a group of muscles such as those in the arms, legs, or neck; or the entire body [8]. • Choreo-athetotic (choreo-athetosis): <i>Chorea</i> is characterized by brief, irregular contractions that are not repetitive or rhythmic but appear to flow from one muscle to the next. Chorea often occurs with <i>athetosis</i>, which adds twisting and writhing movements [9].
Ataxic (ataxia)	People with <i>ataxia</i> experience a failure of muscle control in their arms and legs, resulting in a lack of balance and coordination or a disturbance of gait [10].
Mixed	Some people have a mixture of both abnormal muscle tone and/or involuntary movements. For example, some people with spastic diplegia may have both spasticity and dystonia. CP is classified by the predominant feature: if spasticity is the predominant feature, then the person is said to have spastic CP; if dystonia is the predominant feature, then the person is said to have dystonic CP. However, some people can be classed as having <i>mixed</i> CP where there is no clear predominant feature.

c) Classification of CP on the basis of gross motor function

The final method of classifying CP is on the basis of gross motor function using the Gross Motor Function Classification System (GMFCS). As noted in the previous section, gross motor function involves the movement of the arms, legs, and other large body parts.

The GMFCS is a five-level classification system that describes the functional mobility of children and adolescents with CP [11]. It is based on how children and adolescents move on their own, with emphasis on sitting, transfers (moving from one position to another), and mobility. The GMFCS includes descriptions for five age groups: less than two years, two to four years, four to six years, six to 12 years, and 12 to 18 years. The emphasis is on the child/adolescent's usual performance in their daily environment (i.e., their home and community).³⁴ By choosing which description best matches the child at their current age, a child can be assigned a GMFCS level.

The following are descriptions of the five levels; these correspond to the method that best describes the child's functional mobility after age six. Level I has the fewest movement limitations and level V has the greatest, thus the severity of the movement limitations increases with each increasing level. It is important to note, however, that the differences between the levels are not even.

- Level I Walks without limitations
- Level II Walks with limitations
- Level III Walks using a handheld mobility device
- Level IV Self-mobility with limitations; may use powered mobility
- Level V Transported in a manual wheelchair

Although the levels are based on the method of functional mobility that best describes the child's performance after age six, a child can be classified much earlier using these descriptions.

³⁴ In this context, “community” may be interpreted as “away from home.” Moving about at home is generally easier since home is likely well suited or adapted to the person's needs. The community may be more challenging. It is important to keep in mind the impact of environmental and personal factors on what children and adolescents are able to do in their daily environment (home or community). This was addressed in Section 1.4, The International Classification of Functioning, Disability and Health (ICF).

The following summarizes the commencement of walking for children with CP at GMFCS levels I–III [12]:

- At GMFCS level I, children walk between 18 months and two years without the need for any assistive mobility device.³⁵ (Note that even at GMFCS level I, this is later than for typically developing children, as noted in the gross motor milestones in section 1.5.)
- At GMFCS level II, children aged two to four walk using an assistive mobility device as their preferred method of mobility. At ages four to six, they walk without the need for a handheld mobility device indoors and for short distances on level surfaces outdoors.
- At GMFCS level III, children aged two to four may walk short distances indoors using a handheld mobility device (walker) and adult assistance for steering and turning. At ages four to six, they walk with a handheld mobility device on level surfaces.

The full version of the GMFCS is a short document that contains very useful information. A web link to it is included at the end of this section. The document contains further detail on mobility for each age and GMFCS level. It also includes a summary of the distinctions between each level to help determine the level that most closely resembles a particular child/adolescent's current gross motor function. Web links to videos explaining the GMFCS are also included at the end of this section.

The GMFCS has been proven to be relatively stable over time after age 2 [11]. A recent Swedish study provided further evidence of the stability of the GMFCS [13]. Because the GMFCS level is stable, once a child's GMFCS level is known, it offers insight into what the future may hold in terms of the child's mobility. It helps answer some of the many questions we parents have in the early days, such as, "Will our child walk?" or, "How serious is their CP?"

It is important to note that just as a child's diagnosis of spastic diplegia is generally stable throughout their life, their GMFCS level is generally stable. In other words, the area of the body affected and the severity of the condition (the GMFCS level) generally do not change.

³⁵ Assistive mobility devices (also termed assistive devices, walking aids, mobility aids, and gait aids) include walking sticks (canes), crutches, reverse walker, gait trainer (a device which is more supportive than a walker but less supportive than a wheelchair), and wheelchair.

Traditionally, medical professionals made the assessment, but the *GMFCS Family Report Questionnaire* (web link also included) now allows parents or the young person themselves to do so. Professional and family reports have been shown to be consistent [14]. Useful illustrations have been developed based on the GMFCS for the two upper age bands (six to 12 years and 12 to 18 years) by staff at the Royal Children’s Hospital in Melbourne. See Figures 1.6.1 and 1.6.2.

The SCPE classified walking ability into three levels according to the GMFCS [15]:

- **Mild** Independent walker; GMFCS levels I–II
- **Moderate** Walker with aid; GMFCS level III
- **Severe** Wheelchair; GMFCS levels IV–V

The GMFCS has been translated into many languages and is used all over the world. One of its many advantages is its simplicity. Though the GMFCS is now used in adulthood, particularly in research studies, it has not yet been validated for adults. Hopefully it will be. One study compared the GMFCS level of adults with CP with their GMFCS level at age 12 and found that GMFCS level observed around age 12 was highly predictive of motor function in adulthood [16].

Let us now look at how individuals with spastic diplegia are distributed across the different GMFCS levels. Figure 1.6.3 shows the proportion of children with CP by topography (area of the body affected) and gross motor function (GMFCS level) using data collated from five studies [17–21].

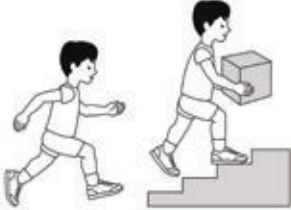
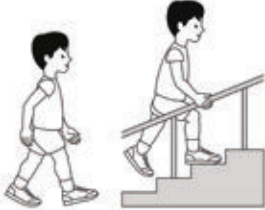



Figure 1.6.3 shows that:

- 36 percent of people with CP had hemiplegia, 36 percent had diplegia, and 28 percent had quadriplegia.³⁶
- Of those with hemiplegia, 96 percent were at GMFCS levels I–III.
- Of those with diplegia, 85 percent were at GMFCS levels I–III.
- Of those with quadriplegia, 27 percent were at GMFCS levels I–III.

Thus this data shows that the majority of individuals with spastic diplegia were at GMFCS levels I–III.

³⁶ In one study [21], the number of people with hemiplegia also included those with monoplegia.

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

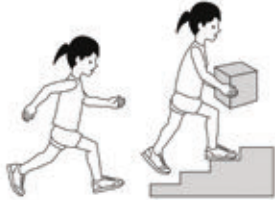




	<p>GMFCS Level I</p> <p>Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.</p>
	<p>GMFCS Level II</p> <p>Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.</p>
	<p>GMFCS Level III</p> <p>Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.</p>
	<p>GMFCS Level IV</p> <p>Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.</p>
	<p>GMFCS Level V</p> <p>Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.</p>

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

Figure 1.6.1 GMFCS E & R between 6th and 12th birthday: descriptors and illustrations. Reproduced with kind permission from K. Graham and K. Willoughby, Royal Children's Hospital Melbourne, Australia.

GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations

	<p>GMFCS Level I</p> <p>Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.</p>
	<p>GMFCS Level II</p> <p>Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.</p>
	<p>GMFCS Level III</p> <p>Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.</p>
	<p>GMFCS Level IV</p> <p>Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.</p>
	<p>GMFCS Level V</p> <p>Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.</p>

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERIC151050

Figure 1.6.2 GMFCS E & R between 12th and 18th birthday: descriptors and illustrations. Reproduced with kind permission from K. Graham and K. Willoughby, Royal Children's Hospital Melbourne, Australia.

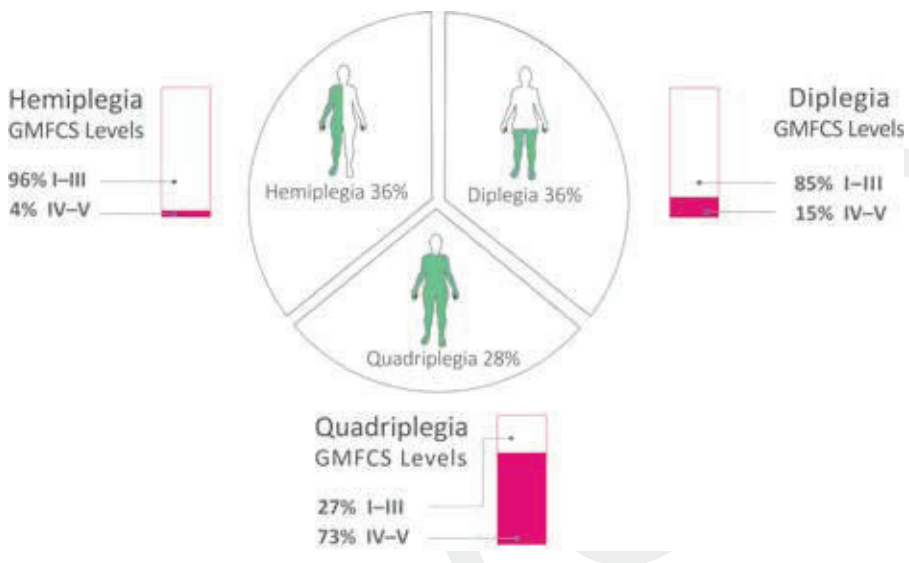


Figure 1.6.3 Proportion of CP by topography (area of the body affected) and severity (GMFCS level). Data collated from five studies [17–21].

As noted earlier, the SCPE subdivided spastic CP into unilateral or bilateral based on whether one or two sides of the body were involved. From the data above, one can broadly assume that:

- At GMFCS levels I–III, the majority of children with bilateral spastic CP have spastic diplegia.
- At GMFCS levels IV and V, the majority of children with bilateral spastic CP have spastic quadriplegia.

This explains why at GMFCS levels I–III the descriptors “spastic diplegia” and “bilateral spastic CP” (or simply “bilateral CP”) can largely be used interchangeably.

Classification systems similar to the GMFCS have since been developed for function in other areas:

- The **Manual Ability Classification System (MACS)** is a five-level classification system that describes how children with CP aged four to 18 years use their hands to handle objects in daily activities [22]. There is a separate **Mini-MACS** for children aged one to four [23].

- The **Communication Function Classification System (CFCS)** is a five-level classification system that describes everyday communication performance [24].³⁷

Web links to the MACS, Mini-MACS, and CFCS are included at the end of this section. Table 1.6.4 summarizes the five levels of the three classification systems (GMFCS, MACS, and CFCS).

Table 1.6.4 Description of the five levels of the GMFCS, MACS, and CFCS [11,12,22,24]

LEVEL	GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM (GMFCS)	MANUAL ABILITY CLASSIFICATION SYSTEM (MACS)	COMMUNICATION FUNCTION CLASSIFICATION SYSTEM (CFCS)
I	Walks without limitations.	Handles objects easily and successfully.	Effective Sender and Receiver with unfamiliar and familiar partners.
II	Walks with limitations.	Handles most objects but with somewhat reduced quality and/or speed of achievement.	Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.
III	Walks using a hand-held mobility device.	Handles objects with difficulty; needs help to prepare and/or modify activities.	Effective Sender and Receiver with familiar partners.
IV	Self-mobility with limitations; may use powered mobility.	Handles a limited selection of easily managed objects in adapted situations.	Inconsistent Sender and/or Receiver with familiar partners.

Cont'd.

³⁷ Communication occurs when a “Sender” transmits a message and a “Receiver” understands the message. In conversation, for example, the Sender is the speaker and the Receiver is the listener. Unfamiliar conversation partners are strangers or acquaintances who only occasionally communicate with the person. Familiar conversation partners such as relatives, caregivers, and friends may be able to communicate more effectively with the person because of previous knowledge and personal experience [24].

LEVEL	GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM (GMFCS)	MANUAL ABILITY CLASSIFICATION SYSTEM (MACS)	COMMUNICATION FUNCTION CLASSIFICATION SYSTEM (CFCS)
V	Transported in a manual wheelchair.	Does not handle objects and has severely limited ability to perform even simple actions.	Seldom-effective Sender and Receiver even with familiar partners.

A study looked at the correlation between distribution of gross motor function, manual ability, and communication function [20]. Table 1.6.5 shows the distribution for children and adolescents with spastic diplegia across the five levels of each classification (GMFCS, MACS, and CFCS).

Table 1.6.5 Distribution of GMFCS, MACS, and CFCS levels for children and adolescents with spastic diplegia

	GMFCS (GROSS MOTOR FUNCTION)	MACS (MANUAL ABILITY)	CFCS (COMMUNICATION)
Level I	38%	44%	55%
Level II	38%	44%	17%
Level III	15%	11%	18%
Level IV	8%	0%	9%
Level V	2%	2%	2%

Data from reference [20].

Table 1.6.5 shows that in this study:

- 91 percent of children and adolescents with spastic diplegia were at GMFCS levels I–III.³⁸
- 99 percent of children and adolescents with spastic diplegia were at MACS levels I–III.

³⁸ Variation is to be expected between studies carried out at different times and in different geographical regions.

- 90 percent of children and adolescents with spastic diplegia were at CFCS levels I–II.
- The distribution across the three classification systems does not precisely correlate. For example, 38 percent of children and adolescents with spastic diplegia were at GMFCS level I, but 55 percent were at CFCS level I. This underscores the important point that the GMFCS does not predict functionality in domains other than mobility. (The same point applies to the MACS and the CFCS.)

Most children with spastic diplegia can be considered to have a mild or moderate (not severe) level of disability with regard to gross motor function (walking ability). Likewise, they can be considered to have a mild or moderate level of disability with regard to manual ability and communication.

We have now looked at the three main classification systems for CP. Of the three, only the GMFCS (and its offshoots, the MACS, Mini-MACS, and CFCS) has been proven to be valid and reliable.

Finally, it should be obvious from the information above that although CP is a single diagnosis, it is far from a uniform condition. Similar to autism, a name change from “cerebral palsy” to “cerebral palsy spectrum disorder” has recently been suggested [25].

Gross motor development curves

The GMFCS led to the development of the gross motor development curves [26,27]. The curves show the change in gross motor function over time as measured by the GMFM-66. There are five curves, one for each GMFCS level. See Figure 1.6.4.

What do the curves show us?

- The curves represent the average GMFM-66 score (y-axis) at each GMFCS level by age (x-axis).
- For each GMFCS level there is an initial rapid rise in GMFM-66 score to a peak level, then the score plateaus (GMFCS levels I–II) or decreases (levels III–V).
- The GMFM-66 score (y-axis) is highest for level I and lowest for level V.

- The dotted lines show the timing of the peak in GMFM-66 score and the decrease from the peak to age 21 years for levels III–V.
- Even a child/adolescent at GMFCS level I does not reach 100, the maximum, on the GMFM-66 scale.

Why are the curves useful? They help answer some of the many questions we parents have in the early days. Knowing our child's GMFCS level at age two, the curves allow us to see how our child's gross motor function, as measured by the GMFM-66, is likely to develop over time.

The curves are based on averages, and while they are very useful, it is important to remember that some children were above and some below the line at each level. While remaining very realistic in our expectations, we should focus on helping our child reach their maximum possible gross motor function, not just hitting the average. The curves should guide, but not limit, our child's potential.

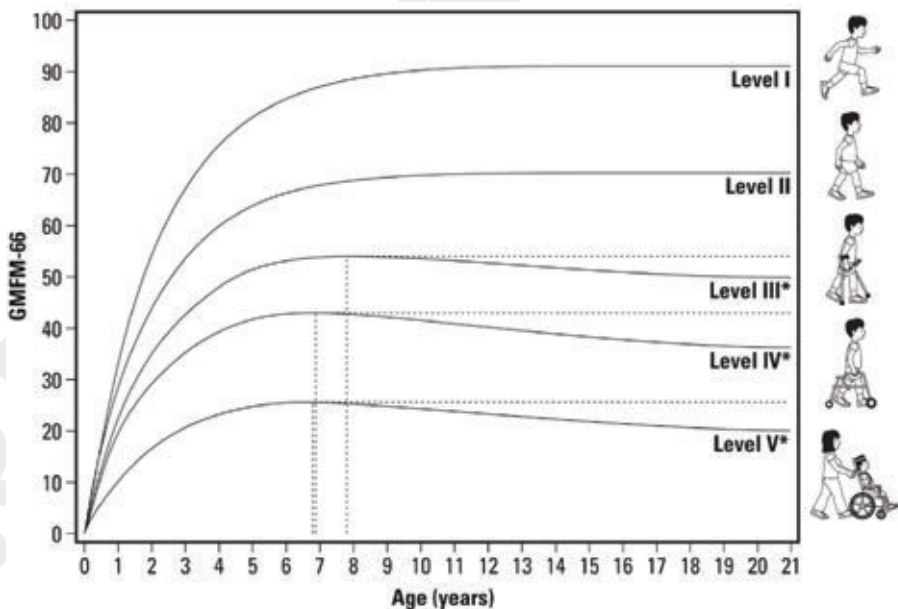


Figure 1.6.4 Gross motor curves in children with CP and the five levels of the GMFCS, modified from Hanna et al. (2008). Reproduced with kind permission from *Cerebral Palsy: Science and Clinical Practice*, edited by Bernard Dan, Margaret Mayston, Nigel Paneth, and Lewis Rosenbloom, published by Mac Keith Press (mackeith.co.uk) in its Clinics in Developmental Medicine Series, 2014, 978-1-909962-38-5.

Tommy was born in 1994. The first GMFCS to age 12 was published in 1997, and the curves were published in 2002. Looking back, I can see how useful they could have been earlier in Tommy's life. Before these tools emerged, questions like, "Will our child walk?" were difficult for professionals to answer; they likely did not want to overpromise.

When I asked whether Tommy would walk, I was told he would walk before age seven but would likely need to use a wheelchair in college. As it turned out, Tommy began to walk independently just after his third birthday and continued to walk independently right through college. (In fact, my favorite photograph from his college graduation is one I took of the family and a friend walking to dinner that evening. It was special because not only was Tommy graduating, he was also walking unaided beside his dad and brothers. I sent a copy of that photograph, with great gratitude, to the many professionals who had treated him over the years.)



Tommy (far left), with a friend and his dad and brothers



Tommy and me

While I do not have a record of his earlier GMFM-66 scores, Tommy's GMFM-66 score just before his 10th birthday was 78. Plotting that score on the curves put him between levels I and II, and at that time he was classed as level II (walks with limitations). This accurately describes how Tommy, now 25, walks today.

Useful web links

- Cerebral Palsy Alliance (2015) *Types of Cerebral Palsy*. [video] youtube.com/watch?v=cOfUGUNxEqU
- CanChild (2007) *Gross Motor Function Classification System Expanded and Revised*. [pdf] canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf
- CanChild (2018) *GMFCS Video*. [video] vimeo.com/293380093
- Cerebral Palsy Foundation (n.d.) *Insights from Experts: Motor Classification*. [video] yourcpf.org/expert-videos/gmfcs/
- CanChild (2011) *GMFCS Family Report Questionnaire*. [pdf] canchild.ca/system/tenon/assets/attachments/000/000/481/original/GMFCS_Family.pdf (Scroll down to find separate sheets for each of the four age groups: 2–4, 4–6, 6–12, and 12–18.)
- MACS (2010) *Manual Ability Classification System for Children with Cerebral Palsy 4–18 Years*. [pdf] macs.nu/files/MACS_English_2010.pdf
- MACS (2013) *Mini-Manual Ability Classification System for Children with Cerebral Palsy 1–4 Years of Age*. [pdf] macs.nu/files/Mini-MACS_English_2016.pdf
- CFCS (2011) *Communication Function Classification System (CFCS)*. [pdf] cfcs.us/wp-content/uploads/2014/02/CFCS_universal_2012_06_06.pdf

Key points Chapter 1

- There are many possible causes of the brain injury that results in CP, including events before and during pregnancy, during birth, or in early infant life.
- Confirmation of the presence of a brain injury by MRI occurs in many but not all cases of CP. Up to 17 percent of people with CP have normal MRI brain scans.
- There seems to be a recent shift toward earlier diagnosis of CP.
- CP is a lifelong condition. There is currently no cure for CP, nor is one imminent.
- A 2013 worldwide review found that the overall prevalence of CP was 2.11 per 1,000 live births.
- Relative to its prevalence and its impact on the life span of those with the condition, funding for CP research is very low.
- The International Classification of Functioning, Disability and Health (ICF) is a very useful framework for CP. It describes human functioning at three levels: body functions and structure, activity, and participation. Environmental and personal factors may influence any of these three levels.
- The World Health Organization (WHO) identified the age at which typically developing children achieve each of the six gross motor milestones. Delay in reaching these milestones is one of the hallmarks of CP.
- One commonly used method for measuring gross motor function in CP is the Gross Motor Function Measure (GMFM). The GMFM can measure and detect changes over time in gross motor function.
- CP may be classified on the basis of topography (the area of the body affected) as monoplegia, hemiplegia, diplegia, triplegia, or quadriplegia. An alternative classification system, also based on topography, classifies CP as unilateral or bilateral.
- CP may be classified on the basis of the predominant feature of the motor impairment. Most studies report that spasticity is the most common type of motor impairment.
- Spastic diplegia is a common subtype of CP, accounting for roughly one-third of cases.
- The GMFCS is a five-level classification system that describes the functional mobility of children and adolescents with CP. The

GMFCS and the gross motor development curves can help predict functional mobility and gross motor function over time.

- The majority of children with spastic diplegia are classified as GMFCS levels I–III: mild or moderate CP.
- At GMFCS levels I–III, the descriptors “spastic diplegia” and “bilateral spastic CP” or simply “bilateral CP” can largely be used interchangeably.
- The GMFCS does not predict function in domains other than mobility.

CHAPTER 2

Spastic Diplegia— Bilateral CP

2.1

Introduction

*Nothing in life is to be feared, it is only to be understood.
Now is the time to understand more, so that we may fear less.*

Marie Curie

I remember a TV advertisement for a particular brand of cider that showed an orchard of trees laden with apples. Its catchphrase was “just add time.” Children with spastic diplegia are born with what appear to be typical bones, muscles, and joints. The problems of spastic diplegia emerge when we “just add time.”

Spastic diplegia is a complex and lifelong condition. There is currently no cure. However, good management and treatment can help reduce its effects. This chapter focuses on the musculoskeletal and mobility issues associated with spastic diplegia from birth through adolescence. A separate chapter is devoted to spastic diplegia in adulthood.

This chapter should contribute to your understanding of how the condition arises and develops over time. It provides much of the information I wish I’d had when Tommy was diagnosed all those years ago.

In his 1991 book, Gage described spastic diplegia as follows [1]:



The involvement is primarily in the lower extremities with relatively normal upper extremity function. The “classic” diplegic child has normal intelligence, absence of seizures, near-normal upper extremity function, and virtually pure spastic involvement. [...] Most diplegic children will walk, although balance, particularly posterior balance, is a much greater problem for these children than for those with hemiplegia. [...] The “typical” gait of a child with diplegia [...] is one of flexion, adduction, and internal rotation at the hips and flexion at the knees. The feet usually have a valgus hindfoot and [...] abducted forefoot.

In their 2007 book, Horstmann and Bleck described it as follows [2]:







When we observe the posture and gait of a child with spastic diplegia anywhere in the world it is as though each child came from the same mold. The common pattern [...] is flexed, adducted, and internally rotated hips [...] We see an increased anterior pelvic tilt, lumbar lordosis, either flexed or hyperextended knees, and equinus.

Table 2.1.1 explains each of the terms used in these descriptions. Together, they paint a picture of spastic diplegia: of a child who walks with flexed knees and hips and whose bones are twisted.

Table 2.1.1 Features of spastic diplegia

TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Posterior balance	Balance in the backward direction is affected. The person often falls backward.	N/A
Lumbar lordosis	An exaggerated inward curve in the lumbar region of the spine, often called a swayback.	
Anterior pelvic tilt	A tipping forward of the pelvis to the front. (The triangle indicates the pelvis.)	

Cont’d.

TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Adduction and internal rotation at the hips	<i>Adduction</i> is movement toward the middle of the body. <i>Internal rotation</i> is a twisting movement around the long axis of a bone toward the middle of the body. With <i>adduction and internal rotation at the hips</i> , the thigh turns inward and toward the middle of the body.	
Flexion at the hips and knees	The hips and knees are bent.	
Hyperextended knees	<i>Hyperextended</i> means beyond straight or over-straightened. This is also termed <i>genu recurvatum</i> . The knee on the left is hyperextended; the knee on the right is normal.	
Abducted forefoot	The front part of the foot moves away (outward) from the back part of the foot. The foot on the left is abducted; the foot on the right is normal.	
Valgus hindfoot	The heels of both feet are turned away from the middle of the body to an abnormal degree; i.e., the heels are turned outward.	
Equinus	The person is walking on their toes.	

This chapter explains how a baby born with what appear to be typical bones, muscles, and joints can grow into a child who fits the descriptions above. I say “appear to be typical” because research is ongoing; there may be slight differences between the bones, muscles, and joints

of a baby with spastic diplegia and those of a typically developing baby. Our understanding may change over time.

This chapter addresses:

- Section 2.2** The brain injury
- Section 2.3** Growth
- Section 2.4** Bones, muscles, joints, and movements
- Section 2.5** Normal walking
- Section 2.6** Primary abnormalities
- Section 2.7** Secondary abnormalities
- Section 2.8** Tertiary abnormalities
- Section 2.9** Walking in individuals with spastic diplegia

Section 2.4 may seem like an anatomy lesson, but because spastic diplegia affects the bones, muscles, joints, and movements, particularly of the lower limbs, a basic understanding helps enormously in understanding both the condition and its treatment. Spastic diplegia also affects mobility, and therefore a basic understanding of normal walking, addressed in section 2.5, is beneficial.

I read the description of spastic diplegia in Dr. Gage's book when Tommy was about five years old. It was a lightbulb moment for me. His assertion that the "classic" diplegic child has normal intelligence was the first positive statement on intelligence in spastic diplegia I had read or heard.

Tommy had a CT scan when he was approximately one year old; phrases like "significant brain damage," "not much active brain," and "go home and mind the other children" conveyed the consultant's concern about what he saw on the scan. I was perplexed: how could this consultant say these things when he had never actually met our very alert and engaging child? It turned out Tommy had normal intelligence.

In the early days we had also been advised to watch out for seizures. Reading Dr. Gage's book, I learned that seizures were not typical in spastic diplegia. Tommy never had a seizure.

Those two descriptions by Drs. Gage, Horstmann, and Bleck described Tommy pretty accurately as a young child. In the early days I thought the way Tommy walked was particular to him. Later, as I observed other people with spastic diplegia, I realized Tommy's manner of walking was characteristic of the condition. The concept that each child with spastic diplegia "came from the same mold" really resonated with me.

In hindsight, the only differences between Tommy and his two older brothers (who do not have spastic diplegia) as a baby were that he cried incessantly for the first three months, he was difficult to feed, and his legs felt strong and stiff from birth. That early stiffness was probably spasticity, though I would only become familiar with the term much later. The photograph below shows our eldest son holding a very rigid Tommy.



“I highly recommend this book to people who have CP, parents, family members, and medical professionals.”

— HANK CHAMBERS, MD

“This detailed and practical book on spastic diplegia, written by a parent in conjunction with medical practitioners at Gillette, is simply brilliant and fills a huge gap.”

— LORI POLISKI, PARENT

“A must-read for parents of children with spastic diplegia, and if its guiding principles are followed, it will do much to ensure that their particular child reaches maturity with an optimal outcome.”

— JAMES R. GAGE, MD

Cerebral palsy (CP) is the most common cause of childhood-onset lifelong physical disability. Approximately one-third of those with CP have the subtype spastic diplegia—also known as bilateral spastic CP, or simply bilateral CP. An estimated 6 million worldwide have spastic diplegia. Until now, there has been no book focused on this condition to help this large group of people. This book focuses on the motor problems—problems with bones, muscles, and joints, and their impact on walking. The Gross Motor Function Classification System (GMFCS) is a five-level system that indicates the severity of the condition. This book is relevant to those at GMFCS levels I to III: those who are capable of walking independently or with a handheld mobility device. These three levels account for the majority of people with spastic diplegia.

The book addresses how spastic diplegia develops over the lifespan and explains the evidence-based, best-practice treatments. It empowers parents of young children, and adolescents and adults with the condition, to become better advocates and co-decision makers in the medical process. The focus of this optimistic, yet practical book is on maximizing activity and participation—living life to its fullest. Health care professionals, educators, students, and extended family members will also benefit from reading this book. Indeed, while this book focuses on spastic diplegia, much of what is addressed also applies to other forms of spastic CP at GMFCS levels I to III, namely hemiplegia and quadriplegia.

Written by Lily Collison, a parent of a son with spastic diplegia and a medical sciences graduate, in close collaboration with senior medical experts from Gillette Children's Specialty Healthcare—a world-renowned center of excellence for CP treatment—this is an excellent, long-needed resource for spastic diplegia.

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