"As relevant to doctors and health professionals as it is to people with cerebral palsy and their families."

—NADIA BADAWI, AM

Gillette Children's Healthcare Series

SPASTIC HEMIPLEGIA

Unilateral Cerebral Palsy

Understanding and managing the condition across the lifespan: A practical guide for families

Marcie Ward, MD
Lily Collison, MA, MSc
Eimear Gabbett, Parent

Editors
Elizabeth R. Boyer, PhD
Tom F. Novacheck, MD

GILLETTE CHILDREN'S

Praise for *Spastic Hemiplegia—Unilateral Cerebral Palsy*

"Wow! This book is the most amazing and comprehensive source of information available for persons with unilateral CP and their families I have ever seen, and it should be required reading for any professionals who care for them. I was frankly astounded by the breadth of information here. Not only did I learn several things I had not known before, but I also am not able to think of anything the authors may have missed. Perhaps even more notable is that the information is understandable and digestible to all audiences and presented in a very caring and respectful manner that does not minimize the inherent challenges of having CP while also highlighting the limitless possibilities. The story of Ally and all the voices of those with CP and their families add tremendously to the content and the overall tone of the book. The lifespan perspective is to be applauded as well."

DIANE DAMIANO, Senior Investigator and Chief, Neurorehabilitation and Biomechanics Research Section, National Institutes of Health; Past-President Clinical Gait and Movement Analysis Society; Past President American Academy of Cerebral Palsy and Developmental Medicine, US

"I found this book to be an exceptional resource. It not only provides a thorough exploration of the unique challenges faced by those of us living with CP but also brings these experiences to life through personal stories and insights. This blend of practical advice and real-life experiences makes it an essential guide for anyone looking to empower themselves or support others in the CP community."

EMMA LIVINGSTONE, Founder and CEO, UP–The Adult Cerebral Palsy Movement; Adult with spastic hemiplegia, UK

"This publication provides a comprehensive review of medical team decision-making and addresses important aspects of surgical and clinical care. Perhaps most importantly, it includes an emphasis on community connection and provides personal experiences from individuals with CP and their families to learn from. Interested individuals, families, and clinicians will benefit from this effort."

JUSTIN RAMSEY, Associate Medical Director, Movement Clinic and Cerebral Palsy Program, Bethany Children's Health Center; Volunteer Clinical Associate Professor of Neurology, University of Oklahoma; Adult with spastic hemiplegia, US

"In a world where it is so hard for parents of children with cerebral palsy to navigate conversations in health care systems, this book gets my highest recommendation: it is useful for parents. In particular, the explanations of concepts that they will hear doctors and therapists refer to, the importance of mental health considerations, and the perspective of other parents make this a uniquely practical resource. An unexpected and wonderful addition is the stories from adults with cerebral palsy—unvarnished and honest—which shed light on their experiences while also offering hope for a positive future for our children and patients."

NATHALIE MAITRE, Professor of Pediatrics in Neonatology, Neonatologist at Children's, and Director of Early Development and Cerebral Palsy Research, Emory University School of Medicine; Mother of son with hemiplegia, US

"How refreshing to read a book that is as relevant to doctors and health professionals as it is to people with cerebral palsy and their families. Learning from real-life experiences like those of Ally and her family, shared with openness and vulnerability, make the book compelling. Their story, interwoven throughout the text, provides valuable insights, and the photographs add depth. This book strikes a balance between being informative and respectful toward health care professionals and people with lived experience, written in language that can facilitate open communication to achieve the best outcome for the child and their family. There is a refreshing emphasis on shared decision-making and multidisciplinary care, as well as family- and person-centered care. A highlight is the information on transition to adulthood and living as an adult with cerebral palsy. It felt like a genuine conversation, addressing the person with CP directly: informative, respectful, and heartwarming. This book just wants to do the right thing by families. It is a generous resource of other sources of knowledge and help. I recommend this book to both health professionals and to families living with cerebral palsy."

NADIA BADAWI, CP Alliance Chair of Cerebral Palsy Research, University of Sydney; Medical Director and Co-Head, Grace Centre for Newborn Intensive Care, The Children's Hospital at Westmead, Australia

"As someone with right spastic hemiplegia, I was amazed by how much of the information was relevant to my memories of childhood therapy appointments and doctor visits. I deeply enjoyed reading the testimonies of those with CP, and I felt recognized inside their stories. From small things like official medical terminology to detailed explanations on why I was receiving certain treatments as a child, this book helped me not only recontextualize my own experiences but also prepared me to be a better medical advocate for myself moving into adulthood."

EMMALYNNE SHUMARD, Student; Adult with spastic hemiplegia, US

"This book is a comprehensive distillation of current medical knowledge and best practice to guide all involved with children, families, and individuals with unilateral cerebral palsy. The delivery is straightforward, organized, and well informed. Individuals with hemiplegia and their parents will be drawn to this one source that focuses on the specifics of the condition. What makes this stand out is the 'humanistic holistic' approach to daily life, which is pertinent to quality of life. Especially noteworthy is the emphasis on activity, sports, and the discussion on how to participate at the community as well as Paralympic level. This book is a unique contribution."

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

"Spastic Hemiplegia—Unilateral Cerebral Palsy *is an essential read for anyone with an interest, either professional or personal, in understanding the condition. It successfully distills a huge volume of research into an accessible text that vitally provides a lifespan perspective. It provides parents with a much-needed toolkit to be their child's advocate. It also equips parents with knowledge to pass on to their child, empowering them to become their own advocate in the future. One of the book's standout features is the inclusion of personal stories. I found myself searching for the personal narrative in each chapter, wanting to understand Eimear's and Ally's perspectives, which brings the robust evidence-based content to life. The book beautifully illustrates what is often said, that each experience of cerebral palsy is unique. The diversity of personal experiences highlights the varied paths to diagnosis, management, and support, as well as both the unique and shared strengths and challenges faced by those living with spastic hemiplegia. This book is a valuable resource that successfully merges scientific evidence with lived experiences, making it a compelling and informative read."*

JENNIFER RYAN, Director, Cerebral Palsy Lifespan Health and Well-being (CP-Life) Research Centre, Royal College of Surgeons in Ireland

"Spastic Hemiplegia *is a perfect primer for parents wanting more information about their child's condition, allied health care professionals interested in gaining more evidence-based information about the care of children with spastic hemiplegia, and for the layperson who knows someone with hemiplegia and is looking to understand the condition better. It is rare to find a book that weaves the patient experience into the content as nicely as has been done in this book. The authors have done a fine job of providing evidence-based information in a patient and family-centered fashion—a must-read for all!"*

BENJAMIN SHORE, Director, Cerebral Palsy and Spasticity Center, Boston Children's Hospital; Associate Professor of Orthopedic Surgery, Harvard Medical School, US

In these days when information is so prolific, misinformation seems to rule. It is no different in the world of cerebral palsy. Sadly, I have seen the wheel being reinvented over and over—erroneous treatment recommendations and overdosed surgeries, proposed and performed by low-volume clinicians and surgeons. Underwhelming treatment outcomes often go unrecognized. Parents and patients seeking comprehensive information on hemiplegia will find in this book clear explanations and sound information on diagnosis, prognosis, treatment strategies, and expected outcomes. I hope that all parents and patients have access to this wonderful work.

PAULO SELBER, Attending Orthopedic Surgeon, Hospital for Special Surgery; Professor of Orthopedic Surgery, Weill Cornell Medical College, US

Being suddenly immersed in a world of medical terminology, professional opinion, and service provision is surely overwhelming. This book centralizes children, families, and adults and provides a wealth of information on living with CP spastic hemiplegia throughout the life course. It has an excellent blend of medical and scientific information, practical application, and real-life excerpts. It is carefully written with clear but thorough explanations. This book is a must-read, not only for parents of children and adults with spastic hemiplegia but for the professionals working with them.

MICHELLE SPIRTOS, Associate Professor and Head of Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin, Ireland

It has been an absolute pleasure to read Spastic Hemiplegia—Unilateral Cerebral Palsy. *The book communicates cutting-edge knowledge about the causes, development, and treatment of cerebral palsy in clear and accessible language. The perspectives of people with CP and their families are thoughtfully integrated. Even the most complex aspects are presented in a way that is easy to understand. I highly recommend this book to families, health care professionals, and researchers studying various aspects of cerebral palsy.*

EVA PONTÉN, Consultant Orthopaedic and Hand Surgeon, Karolinska University Hospital; Associate Professor, Karolinska Institutet, Sweden

SPASTIC HEMIPLEGIA UNILATERAL CEREBRAL PALSY

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To individuals and families whose lives are affected by these conditions, to professionals who serve our community, and to all clinicians and researchers who push the knowledge base forward, we hope the books in this Healthcare Series serve you very well.

Gillette Children's acknowledges a grant from the Cerebral Palsy Foundation for the writing of this book.

All proceeds from the books in this series at Gillette Children's go to research.

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Series Foreword

You hold in your hands one book in the Gillette Children's Healthcare Series. This series was inspired by multiple factors.

It started with Lily Collison writing the first book in the series, *Spastic Diplegia–Bilateral Cerebral Palsy*. Lily has a background in medical science and is the parent of a now adult son who has spastic diplegia. Lily was convincing at the time about the value of such a book, and with the publication of that book in 2020, Gillette Children's became one of the first children's hospitals in the world to set up its own publishing arm—Gillette Children's Healthcare Press. *Spastic Diplegia–Bilateral Cerebral Palsy* received very positive reviews from both families and professionals and achieved strong sales. Unsolicited requests came in from diverse organizations across the globe for translation rights, and feedback from families told us there was a demand for books relevant to other conditions.

We listened.

We were convinced of the value of expanding from one book into a series to reflect Gillette Children's strong commitment to worldwide education. In 2021, Lily joined the press as Program Director, and very quickly, Gillette Children's formed teams to write the Healthcare Series. The series includes, in order of publication:

- *Craniosynostosis*
- *Idiopathic Scoliosis*
- *Spastic Hemiplegia—Unilateral Cerebral Palsy*
- *Spastic Quadriplegia—Bilateral Cerebral Palsy*
- *Spastic Diplegia—Bilateral Cerebral Palsy, second edition*
- *Epilepsy*
- *Spina Bifida*
- *Osteogenesis Imperfecta*
- *Scoliosis—Congenital, Neuromuscular, Syndromic, and Other Causes*

The books address each condition detailing both the medical and human story.

Mac Keith Press, long-time publisher of books on disability and the journal *Developmental Medicine and Child Neurology*, is co-publishing this series with Gillette Children's Healthcare Press.

Families and professionals working well together is key to best management of any condition. The parent is the expert of their child while the professional is the expert of the condition. These books underscore the importance of that family and professional partnership. For each title in the series, medical professionals at Gillette Children's have led the writing, and families contributed the lived experience.

These books have been written in the United States with an international lens and citing international research. However, there isn't always strong evidence to create consensus in medicine, so others may take a different view.

We hope you find the book you hold in your hands to be of great value. We collectively strive to optimize outcomes for children, adolescents, and adults living with these childhood-acquired and largely lifelong conditions.

Dr. Tom F. Novacheck

Series Introduction

The Healthcare Series seeks to optimize outcomes for those who live with childhood-acquired physical and/or neurological conditions. The conditions addressed in this series of books are complex and often have many associated challenges. Although the books focus on the biomedical aspects of each condition, we endeavor to address each condition as holistically as possible. Since the majority of people with these conditions have them for life, the life course is addressed including transition and aging issues.

Who are these books for?

These books are written for an international audience. They are primarily written for parents of young children, but also for adolescents and adults who have the condition. They are written for members of multidisciplinary teams and researchers. Finally, they are written for others, including extended family members, teachers, and students taking courses in the fields of medicine, allied health care, and education.

A worldview

The books in the series focus on evidence-based best practice, which we acknowledge is not available everywhere. It is mostly available in high-income countries (at least in urban areas, though even there, not always), but many families live away from centers of good care.

We also acknowledge that the majority of people with disabilities live in low- and middle-income countries. Improving the lives of all those with disabilities across the globe is an important goal. Developing scalable, affordable interventions is a crucial step toward achieving this. Nonetheless, the best interventions will fail if we do not first address the social determinants of health—the economic, social, and

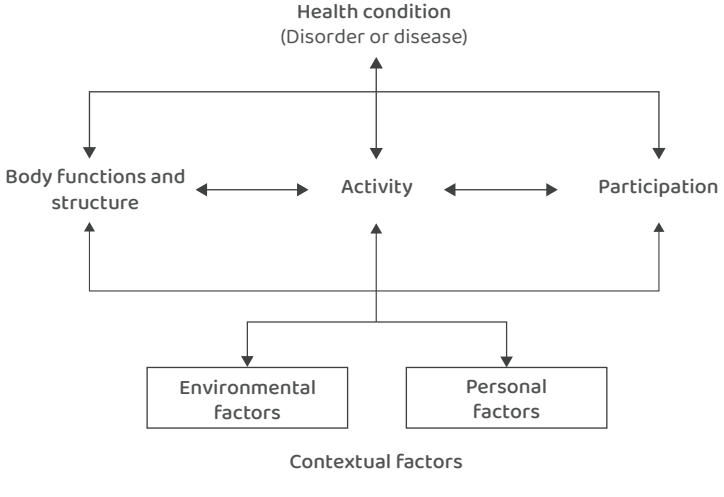
environmental conditions in which people live that shape their overall health and well-being.

No family reading these books should ever feel they have failed their child. We all struggle to do our best for our children within the limitations of our various resources and situations. Indeed, the advocacy role these books may play may help families and professionals lobby in unison for best care.

International Classification of Functioning, Disability and Health

The writing of the series of books has been informed by the International Classification of Functioning, Disability and Health (ICF).[1] The framework explains the impact of a health condition at different levels and how those levels are interconnected. It tells us to look at the full picture—to look at the person with a disability in their life situation.

The framework shows that every human being can experience 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.



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

In health care, there has been a shift away from focusing almost exclusively on correcting issues that cause the individual's functional problems to focusing also on the individual's activity and participation. These books embrace maximizing participation for all people living with disability.

The Family

For simplicity, throughout the series we refer to "parents" and "children"; we acknowledge, however, that family structures vary. "Parent" is used as a generic term that includes grandparents, relatives, and carers (caregivers) who are raising a child. Throughout the series, we refer to male and female as the biologic sex assigned at birth. We acknowledge that this does not equate to gender identity or sexual orientation, and we respect the individuality of each person. Throughout the series we have included both "person with disability" and "disabled person," recognizing that both terms are used.

Caring for a child with a disability can be challenging and overwhelming. Having a strong social support system in place can make a difference. For the parent, balancing the needs of the child with a disability with the needs of siblings—while also meeting employment demands, nurturing a relationship with a significant other, and caring for aging parents—can sometimes feel like an enormous juggling act. Siblings may feel neglected or overlooked because of the increased attention given to the disabled child. It is crucial for parents to allocate time and resources to ensure that siblings feel valued and included in the family dynamics. Engaging siblings in the care and support of the disabled child can help foster a sense of unity and empathy within the family.

A particular challenge for a child and adolescent who has a disability, and their parent, is balancing school attendance (for both academic and social purposes) with clinical appointments and surgery. Appointments outside of school hours are encouraged. School is important because the cognitive and social abilities developed there help maximize employment opportunities when employment is a realistic goal. Indeed, technology has eliminated barriers and created opportunities that did not exist even 10 years ago.

Parents also need to find a way to prioritize self-care. Neglecting their own well-being can have detrimental effects on their mental and physical health. Think of the safety advice on an airplane: you are told that you must put on your own oxygen mask before putting on your child's. It's the same when caring for a child with a disability; parents need to take care of themselves in order to effectively care for their child *and* family. Friends, support groups, or mental health professionals can provide an outlet for parents to express their emotions, gain valuable insights, and find solace in knowing that they are not alone in their journey.

For those of you reading this book who have the condition, we hope this book gives you insights into its many nuances and complexities, acknowledges you as an expert in your own care, and provides a road map and framework for you to advocate for your needs.

Last words

This series of books seeks to be an invaluable educational resource. All proceeds from the series at Gillette Children's go to research.

1.1

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 ¾ percent guaranteed.)
Kid, you'll move mountains!

Dr. Seuss

To fully understand hemiplegia, it is worth first having an understanding of the umbrella term "cerebral palsy" (CP). "Cerebral" refers to a specific part of the brain (the cerebrum) and "palsy" literally means paralysis (cerebrum paralysis). Although paralysis describes something different from the typical features of CP, it is the origin of the term "palsy."

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

At the back of the book, you'll find a glossary of key terms.

A companion website for this book is available at www.GilletteChildrensHealthcarePress.org. This website contains some useful web resources and appendices. A QR code to access **Useful web resources** is included below.

It may be helpful to discuss any questions you may have from reading this book with your medical professional.

USEFUL WEB RESOURCES

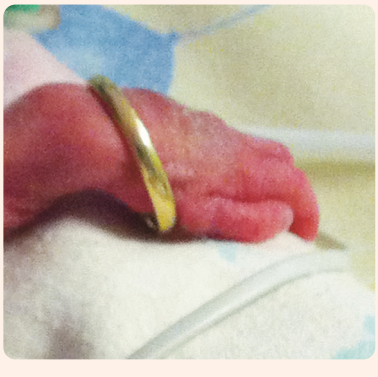
Ally was born prematurely in Limerick, Ireland, on May 2011, at 25 weeks gestation and weighed 2 lb. The early birth was due to cervical insufficiency and a premature rupture of my membranes* with consequent loss of amniotic fluid. I had been in hospital for five days prior to delivery, and because I developed an infection, I had an emergency cesarean section. Following delivery, it was nearly 24 hours before I got to meet Ally in her tiny red hat, in an incubator, and with lots of tubes and machines attached to her. I just could not believe that any baby could be so small; she literally was the size of a soda can with tiny arms and legs.

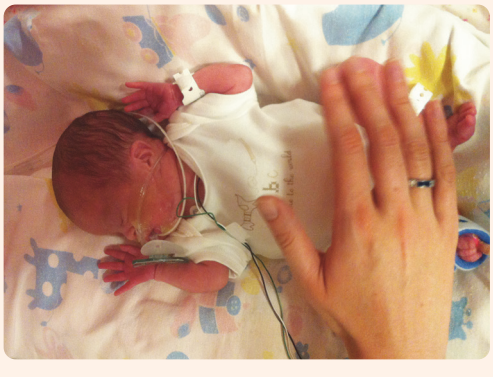
* Cervical insufficiency is a condition where the cervix, the lower part of the uterus, is unable to maintain tight closure during pregnancy, resulting in possible loss of the pregnancy or preterm birth. Premature rupture of membranes occurs when the amniotic sac surrounding and protecting the fetus in the uterus breaks before labor starts, resulting in possible preterm birth and the risk of infection.

Ally was intubated with full life support,* and the clear message we got from the doctors and nurses was how critical the next 24 hours would be. The risk of brain bleeds, breathing issues, and infection was significant, and this would really determine whether Ally would survive.

At the time, this did not mean a lot to me. I did not research or delve into the implications or what it would mean in the future. Instead, I wanted to focus on what I could do to help her there and then, which for me was the immediate focus of generating breast milk and having skin-to-skin contact.

Mom (Eimear) with Ally.





Ally's hand in her dad's wedding ring.

* Life support for a newborn infant typically involves providing mechanical ventilation (a tube down the throat to help with breathing) and other interventions to support vital functions.

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

The title of this book is *Spastic Hemiplegia—Unilateral Cerebral Palsy*. "Spastic hemiplegia" is the term historically used to describe this condition, and it remains in use today in the US. The term derives from "spastic" (the type of high tone), "hemi" (half, referring to one side of the body affected), and "plegia" (the Greek word for stroke). Over the past 20 years, the term "unilateral spastic CP," or simply "unilateral CP," has been adopted in Europe and Australia because it is thought to provide a more accurate description of the condition. "Unilateral" refers to one side of the body being affected. The three terms "spastic hemiplegia," "unilateral spastic CP," and "unilateral CP" are all used in the scientific literature. In this book, written in the US, we use the term "spastic hemiplegia," and since spastic hemiplegia is often referred to simply as hemiplegia, we use both terms interchangeably.

Spastic hemiplegia affects the upper and lower limbs of one side of the body. The upper limb is usually more affected than the lower limb. Spasticity is the most common type of atypical tone present in individuals with hemiplegia, although dystonia can be present as well.

As noted in Chapter 1, the Gross Motor Function Classification System (GMFCS) offers an indication of the severity of the condition. This book is relevant to those at GMFCS levels I and II: those who are capable of walking independently or with an assistive walking device. GMFCS levels I and II account for the majority of individuals with spastic hemiplegia.

Spastic hemiplegia is a complex and lifelong condition. There is currently no cure. However, good management and treatment can help reduce its effects. This chapter explains spastic hemiplegia from birth through adolescence. It should contribute to your understanding of how the condition arises and develops over time. It provides information intended to help parents understand the diagnosis and what to anticipate as their child grows to adulthood. It provides adolescents and adults with an understanding of their condition. Chapter 3 addresses the management of the condition during childhood and adolescence. Chapter 4 is devoted to spastic hemiplegia in adulthood.

Spastic hemiplegia is caused by injury mostly, but not exclusively, to the cerebrum on one side of the brain—the parts of the brain that control voluntary movement, and receive and process sensory information for the opposite side of the body.

Physical features

Gage, an orthopedic surgeon, described the main features of hemiplegia as follows:[74]

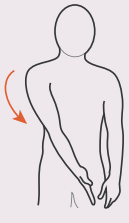
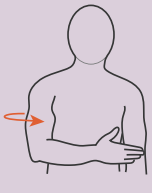
> *In hemiplegia … there is a relatively intact unilateral sensory and motor system; there is not such a problem with overall body balance. The upper extremity is more severely involved than the lower. Typically, the individual walks with a postured upper extremity which is internally rotated at the shoulder, flexed at the elbow, and flexed … at the wrist. The hand is frequently clenched*

with the thumb in the palm … Sensory deprivation is the major problem in the upper extremity … The individual depends totally on the other limb and seems to be almost unaware of the hemiplegic side … The flexed and motionless arm is one of the most distinctive features of hemiplegia …Internal rotation of the lower limb and equinus of the foot and ankle [are typical features].

He added that the affected arm generally remains motionless, unlike the unaffected arm, which swings freely during walking.[74]

Table 2.1.1 explains and illustrates the typical physical features of hemiplegia. Together, these features paint a picture of an individual holding the weaker arm in a flexed position and who walks leading with their stronger leg. Individuals with hemiplegia can have some, but not necessarily all, of these features.

Table 2.1.1 Typical physical features of spastic hemiplegia GMFCS levels I and II

TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Adducted shoulder	The arm is moved inward toward the middle of the body (midline).	
Inwardly rotated shoulder	The upper arm is turned internally toward the body.	

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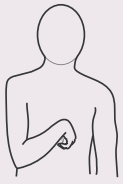
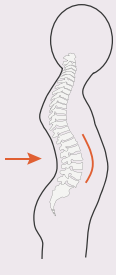
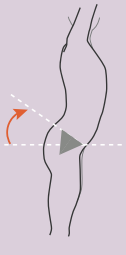
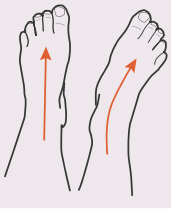
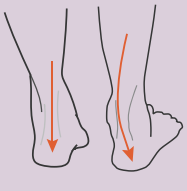
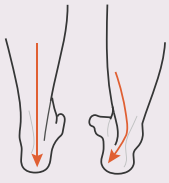
TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Flexed elbow	The arm is bent at the elbow. It is difficult to extend and straighten the elbow.	
Pronated forearm	The hand is in the palm-down position	
Flexed wrist	The wrist is bent downward. It is difficult to extend and straighten the wrist.	
Adducted and flexed thumb	The thumb is bent and positioned toward the middle finger. This is also termed "thumb in palm."	
Flexed fingers	The fingers are folded in toward the palm.	
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.)	
Adduction and internal rotation at the hips	Adduction is movement toward the middle of the body. Internal rotation is a twisting movement around the long axis of a bone toward the middle of the body. With adduction and internal rotation at the hips, the thigh turns inward and toward the middle of the body. The right side shows these features.	

Cont'd.

TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Flexed hips	The hips are bent.	
Hyperextended knee	"Hyperextended" means beyond straight or over-straightened ("back-kneeing"). This is also termed "genu recurvatum." The knee on the left is hyperextended; the knee on the right is typical.	
Flexed knee	The knee is bent. Note that the knee may be *either* hyperextended or flexed.	
Abducted forefoot	The front part (forefoot) of the right foot moves away (outward) from the back part of the foot. The right forefoot is abducted; the left forefoot is typical.	
Valgus hindfoot	The right heel (hindfoot) is turned *away* from the middle of the body to an atypical degree (valgus). The right hindfoot is in a valgus position; the left hindfoot is typical. This is also termed "everted foot" or "eversion."	

Cont'd.

TERM USED IN DESCRIPTIONS	EXPLANATION	ILLUSTRATION
Varus hindfoot	The right heel (hindfoot) is turned *toward* the middle of the body to an atypical degree (varus). The right hindfoot is in a varus position; the left hindfoot is typical. This is also termed "inverted foot" or "inversion."	
Plantar flexed foot	The right toes are pointed downward; the left foot is typical. In walking, this is referred to as toe walking or equinus gait.	

Distribution across classification systems

The effects of the brain injury can extend beyond movement and posture. Several classification systems for individuals with CP were introduced in section 1.7, including classification on the basis of:

- Functional mobility: Gross Motor Function Classification System (GMFCS)
- Ability to handle objects: Manual Ability Classification System (MACS)
- Communication ability: Communication Function Classification System (CFCS)
- Eating and drinking ability: Eating and Drinking Ability Classification System (EDACS)
- Visual function: Visual Function Classification System (VFCS)

Figure 2.1.1 summarizes the percentage distribution of children with hemiplegia across the five levels of the GMFCS, MACS, CFCS, and the EDACS.[43–46,75–78] No data was found for the VFCS.

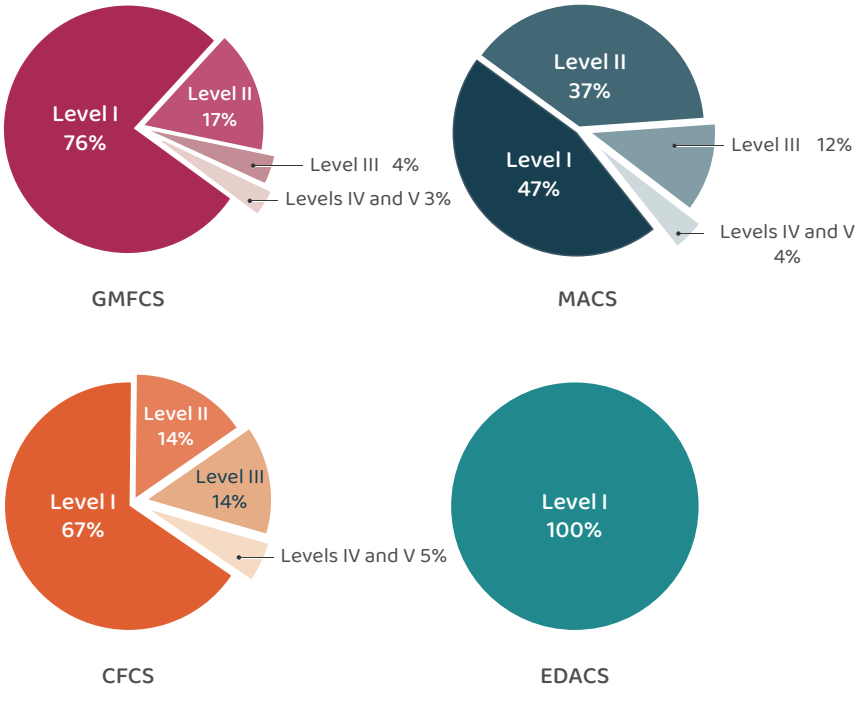


Figure 2.1.1 Distribution of children with hemiplegia across the GMFCS,[43–46,75–78] MACS,[46,76,78] CFCS,[46,78] and EDACS.[78]

Figure 2.1.1 shows that in the studies cited:

- Children with hemiplegia have a high level of gross motor function; almost all (93 percent) were functioning at GMFCS levels I and II.
- Children with hemiplegia have some problems with fine motor ability; however, 84 percent were functioning at MACS levels I and II.
- Children with hemiplegia have some problems with communication; however, 81 percent were functioning at CFCS levels I and II.
- Although the sample size was small (34 children), all children with hemiplegia were eating and drinking safely and efficiently; all were functioning at EDACS level I.

Furthermore, the level at which an individual functions on one of these classification systems can sometimes, though not always, be related to how they function on another. More specifically, one study reported a moderate correlation between GMFCS and MACS but a strong correlation between GMFCS and CFCS in children with hemiplegia.[46]

Co-occurring motor type

With spastic hemiplegia, the predominant motor type is spasticity. However, individuals with spastic hemiplegia sometimes also have co-occurring, or secondary, motor types. Data from the Australian CP register shows that 16 percent of individuals with spastic hemiplegia* have co-occurring dyskinesia, while 1 percent have co-occurring hypotonia.[4] It is believed that the true prevalence of co-occurring motor types is higher[4] and the presence of dystonia with spasticity has been underrecognized.[48] A recent study found that 50 percent of children and young people with CP (all subtypes) had spasticity *and* dystonia.[48] This finding is important because the management of spasticity and dystonia is different.

Associated problems

A large Australian study reported on the prevalence of associated problems (i.e., problems with other body systems) among children aged five with hemiplegia (all GMFCS levels).[79] See Figure 2.1.2.

* For those who acquired CP in the prenatal or perinatal period only; also includes monoplegia.

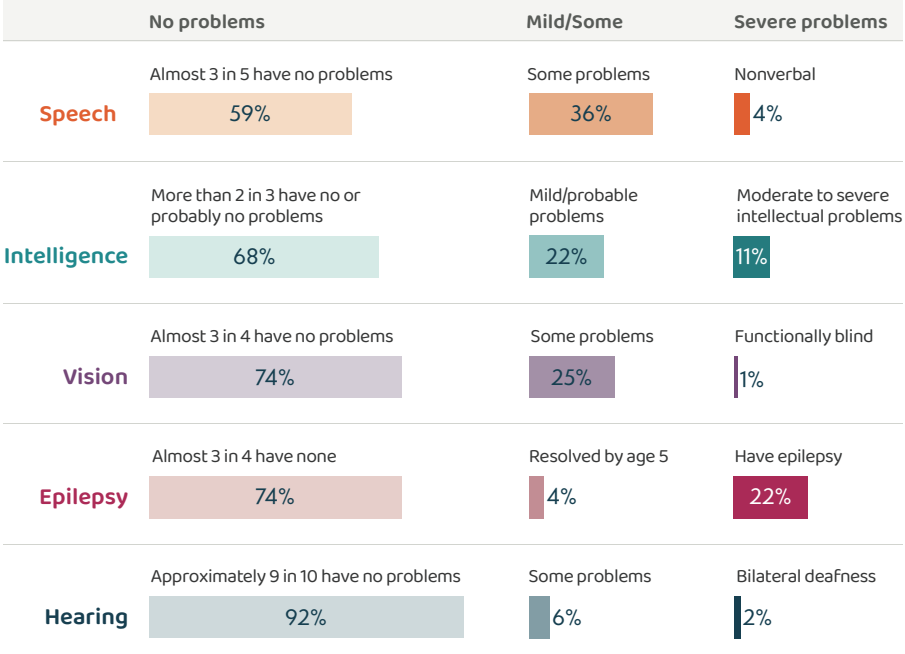


Figure 2.1.2 Prevalence of associated problems among children age five with hemiplegia (all GMFCS levels; data also includes monoplegia).

Figure 2.1.2 shows that a proportion of children with hemiplegia (all GMFCS levels) have problems in the areas of speech, intelligence (cognition), epilepsy, vision, and hearing of varying severity. Not shown in the figure is that more than 90 percent of children had none or only one severe associated problem.[79] As well, the prevalence and severity of associated problems were found to be greater in children at higher GMFCS levels compared with those at lower GMFCS levels.[79] Section 2.10 addresses associated problems in more detail.

Finally, where possible, we cite research studies relevant to those with hemiplegia GMFCS levels I and II. Where studies include multiple subtypes, we aim to give an indication of the proportion of individuals with hemiplegia and/or GMFCS level. Sometimes, we include information about CP in general, where this is deemed useful.

USEFUL WEB RESOURCES

2.2

The brain injury

The greater danger for most of us lies not in
setting our aim too high and falling short;
but in setting our aim too low,
and achieving our mark.
Michelangelo

In terms of brain injuries, *when* and *where* (i.e., the timing in development and the location in the brain) an injury occurs determines the effects and severity of that injury, which translates to the subtype of CP.

There are two types of brain injury commonly associated with hemiplegia: periventricular leukomalacia (PVL) and lesions following middle cerebral artery stroke:[80]

- **Periventricular leukomalacia (PVL):** "Peri" means around, "ventricular" means relating to the ventricles* in the brain, "leuko" means "white," and "malacia" means abnormal softening of tissue.

* Interconnected fluid-filled cavities that produce, circulate, and contain cerebrospinal fluid, which protects the brain and spinal cord.

The full term, "periventricular leukomalacia," describes the injury and means softening of the white tissue (white matter) around the ventricles. The ventricles are the black areas shown in Figure 2.2.1. The injury (orange area) occurs near these ventricles.

- **Middle cerebral artery stroke**. The injury or damage is to the gray matter and/or white matter, following middle cerebral artery stroke.* There are two types of strokes: ischemic and hemorrhagic:
  - An ischemic stroke occurs when a blood vessel supplying the brain is blocked, leading to a lack of oxygen and nutrients to the affected area. "Ischemia" means an inadequate supply of blood to an organ or part of the body.
  - A hemorrhagic stroke occurs when a blood vessel in the brain ruptures and causes bleeding. "Hemorrhage" means the escape of blood from a ruptured blood vessel.

Figure 2.2.1 shows the areas of the body that may be associated with the brain injury of hemiplegia. The white matter in the area of injury includes the motor tracts (that control movement and posture; pink lines in Figure 2.2.1) and sensory tracts (that deliver sensory information; green lines) between the spinal cord and brain. In hemiplegia the brain injury occurs *mostly, but not exclusively*, on one side of the cerebrum.

Because most (though not all) motor tracts cross over at the brain stem and sensory tracts at the spinal cord, an injury to the left cerebrum generally causes right-sided hemiplegia and vice versa. The tracts in the area associated with the brain injury affect both the upper and lower limb on the opposite side.

* The main artery is also commonly associated with adult hemiplegic stroke.

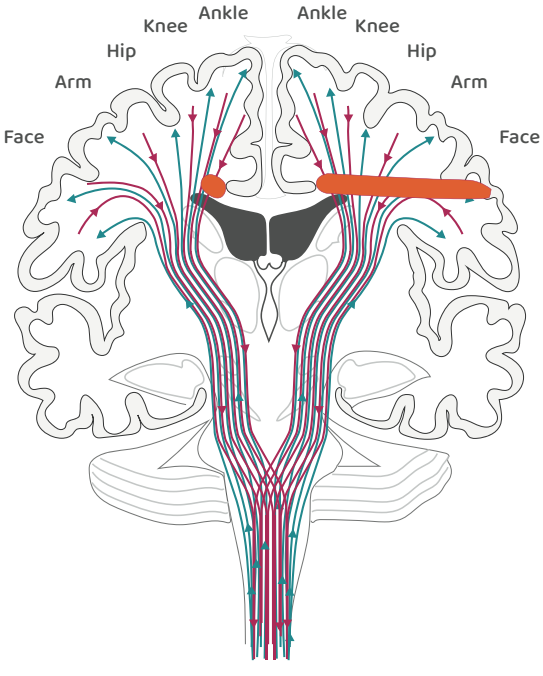
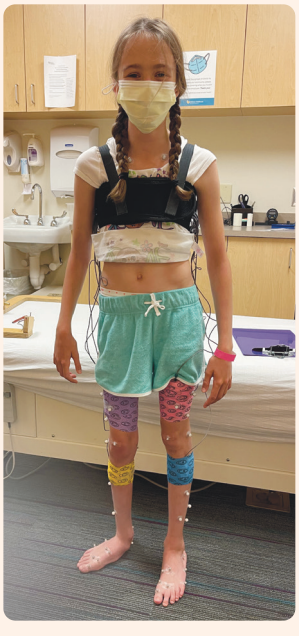


Figure 2.2.1 An example of brain injury resulting in hemiplegia. The motor tracts (pink) descend from the cerebrum to the spinal cord, and the sensory tracts (green) ascend from the spinal cord to the cerebrum. The ventricles are the black areas. The orange area indicates the injury.

It is important to remember that this is a simplified explanation and, in reality, it is much more nuanced, unique to the individual, and complex. For example, there may be more than one area of brain injury. In addition, particularly with preterm birth, brain injury may happen more than once. The timing in development when the injury occurs is important because the areas of the brain that are developing at the time of the injury are the most vulnerable.

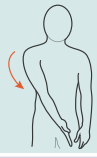
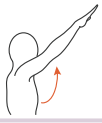
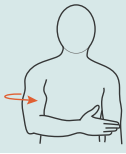
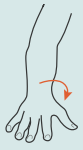
Ally's diagnosis of cerebral palsy due to periventricular leukomalacia as given by the pediatrician was very matter of fact and technical. While understanding the technicalities of CP is very important, it is essential to remember that every child is different, and assessments must be part of a holistic overview of a child's development. Over the years, Ally has had a variety of such assessments, including measurements, gait analysis,* etc. These are very important, especially during growth spurts, which in Ally's case, really have had an impact on her physical development. I can certainly see that as she is coming into her teenage years and growing weekly that there is a significant impact on her gait and tone. This makes these measurements extremely important as they give a continual overview of changes and allow for modifications to orthoses.

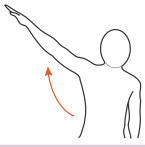
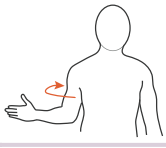
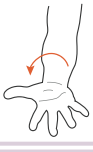
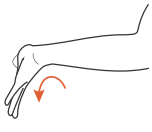
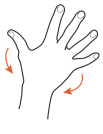


Ally having her gait analysis before surgery, age 11.

* A measurement tool used to evaluate gait. Within gait analysis, multiple variables are evaluated using different measurement tools.

Table 2.4.1 Upper limb movements, joint ROMs,[93] and key muscles

MOVEMENT (Green background indicates movements affected by spasticity *on the involved side* in hemiplegia)		KEY MUSCLES RESPONSIBLE FOR THE MOVEMENT (Two-jointed muscles are indicated in orange)
Shoulder adduction Movement of the arm toward the middle of the body (midline) **ROM 0 to 140 degrees**		**Shoulder adductors** • Latissimus dorsi • Teres major • Pectoralis major
Shoulder flexion Movement of the arm upward toward the face **ROM 0 to 180 degrees**		**Shoulder flexors** • Pectoralis major • Deltoid
Shoulder internal rotation Movement of the upper arm internally toward the middle of the body (midline) **ROM 0 to 70 degrees**		**Shoulder internal rotators** • Latissimus dorsi • Teres major • Pectoralis major
Elbow flexion Movement of the forearm toward the upper arm **ROM 0 to 150 degrees**		**Elbow flexors** • Biceps • Brachialis • Brachioradialis
Forearm pronation Internal rotation of the forearm that results in the hand moving from the palm-up to the palm-down position **ROM 0 to 80 degrees**		**Pronators** • Pronator teres • Pronator quadratus
Wrist flexion Movement of the palm of the hand toward the inside of the forearm **ROM 0 to 80 degrees**		**Wrist flexors** • Flexor carpi radialis • Flexor carpi ulnaris • Palmaris longus
Thumb adduction Movement of the thumb toward the fingers **ROM 0 to 80 degrees** **Thumb flexion** Movement of the thumb into palm **ROM 0 to 50 degrees** **Finger flexion** Movement of the fingers toward the palm **ROM 0 to 90 degrees**		**Thumb adductors** • Adductor pollicis **Thumb flexors** • Flexor pollicis longus • Flexor pollicis brevis **Finger flexors** • Flexor digitorum superficialis • Flexor digitorum profundus

OPPOSITE MOVEMENT		KEY MUSCLES RESPONSIBLE FOR THE OPPOSITE MOVEMENT
Shoulder abduction Movement of the arm away from the middle of the body (midline) **ROM 0 to 45 degrees**		**Shoulder abductors** • Supraspinatus • Deltoid
Shoulder extension Movement of the arm to the back of the body **ROM 0 to 60 degrees**		**Shoulder extensors** • Deltoid • Latissimus dorsi • Teres major
Shoulder external rotation Movement of the upper arm externally away from the middle of the body (midline) **ROM 0 to 90 degrees**		**Shoulder external rotators** • Infraspinatus • Teres minor
Elbow extension Movement of the forearm away from the upper arm **ROM 0 to 150 degrees**		**Elbow extensors** • Triceps
Forearm supination External rotation of the forearm that results in the hand moving from the palm-down to the palm-up position **ROM 0 to 80 degrees**		**Supinators** • Supinator
Wrist extension Movement of the palm of the hand away from the inside of the forearm **ROM 0 to 70 degrees**		**Wrist extensors** • Extensor carpi radialis • Extensor carpi ulnaris • Extensor carpi radialis brevis
Thumb (radial) abduction Movement of the thumb away from the fingers **ROM 0 to 80 degrees** **Thumb extension** Movement of the thumb away from the palm **ROM 0 to 50 degrees** **Finger extension** Movement of the fingers away from the palm **ROM 0 to 90 degrees**		**Thumb abductors** • Abductor pollicis longus • Abductor pollicis brevis **Thumb extensors** • Extensor pollicis longus • Extensor pollicis brevis **Finger extensors** *Individual muscles not listed*

2.5

Typical hand function and typical walking

The hand is the cutting edge of the mind.
Jacob Bronowski

Typical hand function

Our hands are the tools we use to play and do work and to perform many activities of daily living (ADLs), which are the essential self-care tasks typically performed daily, such as bathing, dressing, grooming, eating, and toileting. Our hands are important because they provide sensation and movement. Effective development of hand skills depends on adequate postural mechanisms, cognition, visual perception, and tactile ability.* Hand use is complex and involves intricate coordination of the senses and muscles to perform tasks, such as:

* **Postural mechanisms** are the system of muscles, joints, and sensory feedback that the body uses to maintain balance and upright posture while sitting, standing, or moving about. **Visual perception** is interpreting and making sense of visual information from the environment by the brain. **Tactile ability** refers to the sense of touch and the ability to perceive and interpret physical sensations through the skin, providing information such as light touch, deep touch, temperature, vibration, and pain.

- **Grasping:** Using the fingers and thumb to hold onto an object. There are several types of grasps, such as palmar, pincer, and lateral, which depend on the shape and size of the object being grasped:
  - Palmar grasp: Holding an object using the palm and fingers
  - Pincer grasp: Holding an object between the tips of the index finger and thumb
  - Lateral grasp: Holding an object between the side of the index finger and the thumb (such as someone might hold a key)
- **Carrying:** Transporting a handheld object from one place to another
- **Releasing:** Letting go of an object. There are two types of releases: power and precision release:
  - Power release: quick and forceful
  - Precision release: more controlled and gradual
- **Manipulating:** Moving and positioning an object within the hand (e.g., turning a key, opening a door, using a pen).

Bilateral hand use involves both hands in a task. The term "bimanual activities" is also used to describe activities that involve both hands.

In addition, the task of maintaining balance, while sitting, for example, is very important for reaching and grasping. In the sitting position the body functions as an anchor for all the levers that are used in arm movements.

Typical walking

In general, we take walking for granted. It is only when we encounter a problem that we stop to think about what walking entails. The term "gait" refers to a person's manner of walking. "Typical" gait refers to the typically developing person's manner of walking, which has been studied extensively. Because having problems with walking is one of the hallmarks of spastic hemiplegia, this section briefly looks at the features of typical walking.

Walking is a phenomenal achievement. It involves generating forces, managing gravity, speed, balance, and more. In evolutionary terms, walking on two limbs was advantageous because it freed our upper limbs for other tasks. It is no surprise that crawling comes before walking in human gross motor development: a crawling child has four limbs

on the floor and is therefore more stable. Walking, which involves balancing on two limbs, is a more advanced and more demanding form of movement.

a) The requirements of walking

Walking has four requirements:[96]

- **A control system:** The nervous system provides the control system for walking.
- **An energy source:** The energy required is supplied by oxygen* and the breakdown of food.
- **Levers providing movement:** The levers are the bones.
- **Forces to move the levers:** Muscle contraction provides the forces for walking. As we saw in the previous section, movement is generated by muscle forces acting on the levers (the bones).

b) The gait cycle

One complete gait (or walking) cycle refers to the time between two successive occurrences of the same event in walking—for example, the time between when one foot strikes the ground and when that same foot strikes the ground again. Figure 2.5.1 shows what is happening with each limb during a complete gait cycle. The gait cycle is divided into two major phases:

- **Stance phase:** The period of time the foot of interest (green in Figure 2.5.1) is on the ground
- **Swing phase:** The period of time the foot of interest is in the air

Stance phase occupies approximately 60 percent of the gait cycle, and swing phase occupies approximately 40 percent.[96] There are two periods in the gait cycle when both limbs are on the ground; this is termed "double stance" (or "double support"). Single stance (or single support) is when just one limb is on the ground. Walking involves alternately balancing on each single limb as we move forward.

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* Energy can be produced without oxygen in some cases; for example, for short bursts of quick walking. This is termed "anaerobic metabolism."

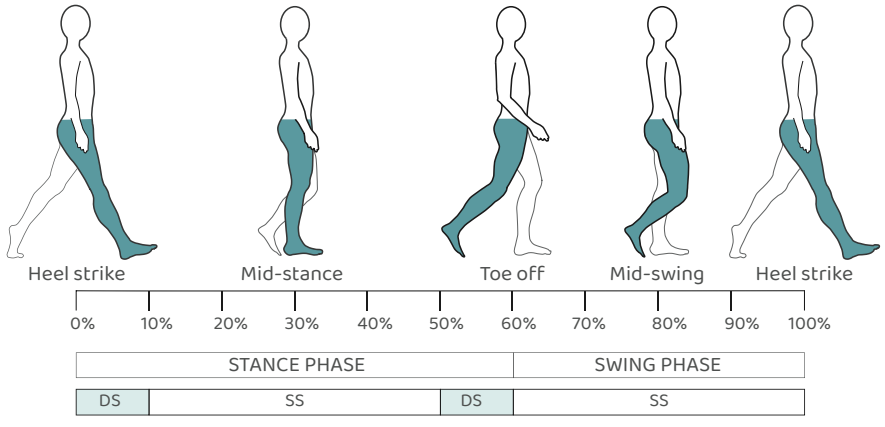

Figure 2.5.1 A complete gait cycle. "DS" is double stance; "SS" is single stance.

c) Attributes of typical walking

The following are attributes of typical walking that are frequently lost in individuals with spastic hemiplegia:[96]

- **Stability in the stance phase:** A reflection of controlled movement and good balance
- **Foot clearance in the swing phase:** Movement of the foot forward without dragging the toe
- **Pre-positioning of the foot for initial contact (heel strike):** Preparation of the foot to strike the ground with the heel (see Figure 2.5.1)
- **Adequate step length:** A sufficiently long step taken
- **Energy conservation:** Energy-efficient walking

Problems with the first four of these attributes contribute to problems with the fifth, the energy cost of walking.

When a typically developing child begins to walk, they do so without these attributes. The knees are relatively stiff and they walk with a wide base of support (i.e., the legs are far apart). But as the child develops balance and their motor system matures, their gait evolves toward the adult pattern, generally by about three and a half years of age.[97] It appears that walking is innate rather than learned, and it depends on the progressive maturing of the central nervous system.

I would say to parents that you do need great patience with children with CP as they have to put so much energy into physical movement and development. This can sometimes slow down their development in other areas such as speaking or with their schoolwork. I've gone to parent-teacher meetings over the years and been given feedback about concerns regarding Ally's reading, maths, or executive functioning, and then been amazed the following year when, quite often, Ally has caught up.

People may assume that kids with CP have the same capabilities as everyone else when they are in mainstream school. In many ways they do, and certainly for Ally, her tenacity and determination support this perception. But we also need to be conscious, understanding, and supportive of their limitations. Our physiotherapist joined me for a school appointment with Ally's teacher on one occasion, and as we walked out to the car together after the meeting, she remarked that she wasn't sure that people understand how much harder Ally has to work just to sit up straight or to try to keep up with the other kids. This level of effort can be formally measured through oxygen consumption levels when children with CP carry out normal activities. When Ally was assessed, her oxygen consumption (a measure of energy expenditure) was approximately one and a half times higher than for kids with typical development. This measurement is an excellent way to show how much harder children with CP have to work to accomplish everyday tasks.

Key points Chapter 2

- Spastic hemiplegia affects the upper and lower limbs of one side of the body. The upper limb is usually more affected than the lower limb.
- Studies show that children with hemiplegia have a high level of gross motor function—93 percent were functioning at GMFCS levels I and II. They have more problems with fine motor ability; however, 84 percent were functioning at MACS levels I and II.
- Spasticity is the most common type of atypical tone present in individuals with hemiplegia, although dystonia can be present as well.
- Spastic hemiplegia is caused by injury mostly, but not exclusively, to the cerebrum on one side of the brain—the parts of the brain that control voluntary movement and receive and process sensory information for the opposite side of the body.
- There are two types of brain injury commonly associated with hemiplegia: periventricular leukomalacia (PVL) and lesions following middle cerebral artery stroke.
- A minority of children with hemiplegia (all GMFCS levels) have problems of varying severity in the areas of speech, intelligence (cognition), epilepsy, vision, and hearing. However, more than 90 percent of children have none or only one severe associated problem. These and other associated problems may reduce well-being far more than motor problems.
- A useful framework for classifying the musculoskeletal problems that occur in children with spastic CP categorizes them into primary, secondary, and tertiary problems. Primary problems are caused by the brain injury and are therefore present from when the brain injury occurred. Secondary problems develop over time in the growing child. They are problems of atypical muscle growth and bone development and are referred to as "growth problems." Tertiary problems are the "coping responses" that arise to compensate for or counteract the primary and secondary problems.
- A nine-level classification system describes the functional use of the involved upper limb, and a four-group classification system describes the gait patterns in individuals with spastic hemiplegia.

3.8

Orthopedic surgery

He jests at scars that never felt a wound.
William Shakespeare

Single-event multilevel surgery (SEMLS) involves multiple orthopedic surgical procedures performed during a single operation. The goals are for the surgeon to identify and correct all the muscle and bone problems in the same surgery to avoid multiple hospital admissions, repeated anesthesia, and multiple rehabilitations. SEMLS is now considered best practice for orthopedic surgery in CP.[129]

This section addresses both upper limb and lower limb orthopedic surgery in children and adolescents with hemiplegia GMFCS levels I and II. SEMLS is more frequently needed for the lower rather than the upper limb. It may be possible to combine upper and lower limb orthopedic surgery, but several factors must be considered, including:

- Optimum timing for each does not always coincide.
- Following surgery, function takes time to recover. A reduction in function (albeit temporary) in both the arm and leg on the affected side could leave the child or adolescent unsafe for navigating their

environment with greater postoperative care and rehabilitation challenges (e.g., if both upper and lower limb are in casts).
- Treatment needs to be coordinated if two areas of the body are operated on. Surgeons in CP usually specialize in either upper or lower limb surgery, not both, so different specialists need to be coordinated. This is possible at some specialist centers but is not always logistically possible. An example of where coordinating treatment is necessary is that arm swing is an integral part of gait, and elbow contracture can contribute to abnormal gait in the individual with hemiplegia.
- Similar coordination is needed for rehabilitation, as occupational therapists largely look after the upper limb while physical therapists look after the lower limb.

Orthopedic surgery can involve soft tissue and bone surgery.

Soft tissue surgery can include:

- **Tendon release:** Severing the tendon of a contracted muscle to allow for a greater range of motion of the joint. Once the tendon is severed, the function of the muscle is markedly diminished, which therefore decreases the problematic pull of the muscle.
- **Tendon transfer:** Reattaching the tendon at a different point to change the function of the muscle. For example, a muscle that behaved as a joint flexor, when transferred, could become a joint extensor. The goal is to improve the balance of muscles around a joint.
- **Muscle and/or tendon lengthening:** Lengthening the muscle and/or tendon, though not releasing the tendon entirely, allowing for continued action of that muscle.
- **Muscle recession:** Dividing the sheet of tissue where the muscle ends and the tendon begins. This is most commonly done in the calf, with the sheet of tissue of the gastrocnemius being separated from a similar sheet for the soleus (as they come together at their common Achilles tendon) and only the gastrocnemius tissue (the two-joint muscle) being divided.

It is important to note that with tendon release or muscle and/or tendon lengthening surgery, variable degrees of weakness occur, and with further growth, the contracture may recur.

Bone surgery can include:

- **Osteotomy:** Surgical cutting of a bone
- **Fusion:** Permanently joining two or more bones to eliminate joint movement and provide stability, also termed "arthrodesis"

Upper limb orthopedic surgery

The goals of upper limb orthopedic surgery include improving upper limb function and positioning to facilitate gait and enhance self-image or ease of daily cares.* For example, surgery may improve reach, grasp, release, or pinch, all of which help with functional tasks. It's important that the individual, family, and the multidisciplinary team agree on realistic goals, taking into account the child's present level of function, and understanding that while surgery may improve it, it will not restore full hand function.

Evaluation for upper limb surgery at Gillette Children's includes the following:

- Medical history
- Physical examination, which involves both a motor and sensory evaluation including, for example, active and passive range of motion, presence of spasticity, dystonia, contractures, selective motor control, muscle strength, and sensory deficits
- Functional questionnaire (e.g., House upper limb functional use scale)
- Parent-reported functional questionnaires for children (self-reported by older individuals where possible)
- Evaluation of arm and hand movement, which can be done by videotaping and then review; for example:
    - The SHUEE or Melbourne videotape assessment.†

* Daily activities such as dressing, feeding, toileting, and cutting nails, completed by the individual themselves, or supported by a caregiver.

† The SHUEE (Shriners Hospital Upper Extremity Evaluation) videotapes upper extremity function (e.g., position, grasp, and release). The Melbourne videotape assessment is similar.

  - Motion analysis: two-dimensional* video combined with electromyography (EMG) in real time. EMG measures the activity of muscles. Measurement is taken while the child performs functional tasks. This is normally completed in a motion analysis laboratory.†
- X-rays of the joints or limbs, sometimes to assess growth plate status

Once a full evaluation is done, a customized treatment plan is developed. Several surgical procedures are commonly necessary for the affected upper limb, and they are normally carried out together in a SEMLS.

Typical procedures at the shoulder, elbow, forearm, wrist, hand, thumb, or finger level may include:

- Soft tissue surgery (tendon release, tendon transfer, muscle lengthening)
- Bone or joint (osteotomy or fusion)
- Neurectomy (severing of a nerve, partial or complete)

Common upper limb abnormalities and their appropriate surgeries include:

- Elbow flexion: surgical lengthening or release of elbow flexor muscles
- Forearm pronation: surgical release of pronator teres muscle
- Wrist flexion:
  - Surgical release or lengthening of wrist flexor muscles
  - Tendon transfers of wrist flexor muscles to wrist extension
  - Wrist fusion (usually adult with fixed contracture)
- Thumb in palm and finger flexion: surgical lengthening or release of muscles, with possible tendon transfer

Rehabilitation after surgery may involve casting, orthoses/splinting, and therapy to maximize results.

A comparison of the preoperative and postoperative scores on the House upper limb functional use scale in 85 individuals with hemiplegia who had upper limb surgery showed an average improvement of 2.7 functional levels.[245] For example, this would mean that hand function

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* Front and side views.

† Note that upper extremity motion analysis varies among centers.

improved from a good passive assist (can hold object and stabilize it for use by other hand) into hand function as a good active assist (can actively grasp object and manipulate it). Smitherman and colleagues reported satisfaction with both functional and cosmetic outcomes in children with hemiplegia who had SEMLS.[246] Van Heest and colleagues reported that tendon transfers, especially for wrist extension, can be beneficial in improving upper extremity joint positioning in children with spastic hemiplegia. However, residual impairment in hand function can persist.[247]

Subsequent surgery to address changes with growth and development may be necessary if changes occur over time.

Lower limb orthopedic surgery

There are two main peaks in the management of the musculoskeletal problems affecting gait. The first occurs in early childhood, when tone reduction (in conjunction with other treatments such as PT and orthoses) is very important. The second occurs in later childhood (at approximately 8 to 12 years) when orthopedic surgery may be needed to address the secondary problems—the muscle and bone problems that have developed.[193]

Delaying orthopedic surgery allows motor patterns to mature, and by this stage the gains from tone reduction have largely been achieved. Delaying orthopedic surgery is also important because it helps avoid the unpredictable outcomes of early surgery.[229] Orthopedic surgery becomes necessary when the muscle and bone problems (the secondary problems) can no longer be adequately managed by more conservative means, and they are having a significant adverse effect on gait and function.

We now address:

a) **Three-dimensional gait analysis**
b) **Lower limb single-event multilevel surgery (SEMLS)**

Key points Chapter 4

- CP is diagnosed in infancy and is a lifelong condition. It is often thought of as a children's condition, but it is not. If one considers a normal life span, for every child and adolescent with CP there are approximately three adults with the condition.
- As a person with hemiplegia reaches adulthood and skeletal growth has ceased, a certain stabilization of the musculoskeletal aspects of the condition occurs. The rate of change of the condition is slower in adulthood, assuming the adult remains physically active. People with hemiplegia may, however, develop secondary conditions in adulthood. Some are consistent with typical aging, some may be unique. Each may influence body systems in more complex ways because of the interactions with CP itself.
- Examples of the decline that may occur with typical aging include sarcopenia, joint pain, osteoarthritis, osteoporosis, falls, and low-trauma fractures. Many conditions become more prevalent as people age, including cardiovascular disease, cancer, respiratory disease, and diabetes. These conditions are termed "noncommunicable diseases."
- Adults with hemiplegia have had their condition since childhood, but they are also susceptible to the same challenges of typical aging. For the person with hemiplegia, it is almost as if, on entering adulthood, two roads converge: the challenges of growing up with the condition meet the challenges of typical aging. The adult with hemiplegia must manage these two sets of challenges in combination. The problems of aging may occur at a younger age and with more severity in adults with CP than in those without the condition.
- The prevalence of several chronic physical and mental health conditions has been found to be higher among adults with CP than those without CP. However, much can be done to prevent or minimize many of the secondary conditions that can arise.

Chapter 5

Living with spastic hemiplegia

We read to know we are not alone.
C.S. Lewis

In this chapter, people share stories of living with spastic hemiplegia.

Kelly, mother of six-year-old Leo, from Minnesota, US

We never anticipated this. My pregnancy was very normal—no illness, a normal level of life stress, no falls, nothing that would lead me to think Leo would have any differences relative to his two siblings. Leo's birth was even the most uneventful of all three of our children because he actually came out as planned on his scheduled C-section date without any complications. I had had a very traumatic birth experience with his older brother five years prior, which led to an emergency C-section, and then another C-section for his sister three and a half years later, even though she tried to come on her own. Leo was the one who stuck with the plan and let us do what was needed to keep us both as safe as possible during delivery.

He was also a very normal baby. It was maybe harder to get him on a schedule, but it often is for a third child with so much going on in a growing family. It wasn't until he was around five or six months old that I started to notice some things: he seemed slouchier and not really interested in rolling or moving too much, and he was starting to grab for things, but always with his right hand, never his left. I looked back on his siblings' five- and six-month milestone pictures that showed them both sitting up straight, and videos that showed them more mobile. But Leo was super happy and sleeping and eating well, so I didn't get too worked up about it.

I brought up my observations at our six-month wellness check with the pediatrician. Initially, she didn't show concern and explained that

it can be normal for a baby to favor one side. She advised us to give it a little more time but said that if we felt there was anything we wanted to check out further, she would give a referral for Leo to be seen by other specialists. As he was still pretty young and with no real obvious reasons for delays, we all hoped he would catch up by the next visit. The plan was to check in again at nine months.

We didn't wait that long. Just one month later, when Leo was seven months old, I called our pediatrician to say that we were now obsessively watching him and he for sure was not even trying to use his left hand. I also noticed that his left leg wasn't really kicking when he was lying on his back or putting his feet in the water. This seemed different from his siblings, and I wanted to know why. With no hesitation, the pediatrician wrote the referral for physical therapy and neurology.

I understood the relationship between what we were noticing with Leo and the referral to physical therapy, but "neurology" was a big new word for me that I didn't correlate to our concerns. Our pediatrician explained that they could be looking for something brain related, which had not been on my radar. It was then I began to worry.

I called to make the neurology appointment on May 25, 2018, and was told by the scheduler, who was very pleasant and calm, that we couldn't get in until August 26. I thought, WHAT? That felt like having to wait 10 years considering the rapid pace of change in babies. The thought of having to wait three months to have someone see what was going on with Leo simultaneously broke my heart and made me furious. When I asked the scheduler what I was supposed to do in the meantime, she found earlier availability with a nurse practitioner of neurology for June 18. I took that appointment while also still hanging onto the August date with the neurologist, just in case.

The day finally came, and the nurse practitioner asked a lot of questions about my pregnancy and when we first noticed changes with Leo. She completed a physical exam of him and determined that his reflexes weren't where they should be and that he had higher tone in his limbs. She recommended an MRI as a next step.

It was at this appointment with the nurse practitioner that I first heard the words "cerebral palsy," which caught me completely off guard.

I got the sense that the possibility of CP was told to a lot of families because she immediately explained that it was not an official diagnosis, but that she wanted me to be aware. In my uneducated mind at the time, my first thoughts were about extreme lack of mobility and confinement to a wheelchair. I soon learned that CP is a spectrum with the impacts being varied.

As I got in the car to drive home, I became completely overwhelmed with the confirmation that something did actually seem wrong with my baby. I sobbed most of the way home, releasing weeks of emotions that I had been suppressing.

The MRI was scheduled about a month later. Leo was sedated for it and very groggy after the 90-minute procedure. We weren't allowed in the room with him. Afterwards, we took him home and waited for about a week for the results. Our hope was that the MRI would provide some answers, of course: if it showed nothing of concern, we knew Leo would have to have other tests to try to find answers.

When the nurse practitioner called, she said the MRI was successful in that it showed something even if what it showed was hard to comprehend. She explained that Leo had what appeared to be an old brain bleed on his right frontal lobe, which accounted for his left side weakness. The likely explanation for the bleed was that Leo had had a perinatal stroke. While this result was very surprising to us, we felt lucky to have this answer when Leo was just nine months old.

Out of precaution, we met with a pediatric neurosurgeon to make sure the brain bleed was contained and that there were no areas of concern. The doctor gave us the good news that there didn't seem to be any reason to operate as all the images pointed toward an old and contained injury. It was then that we felt like we could move ahead.

Finally, the August 26 appointment that I had kept became an opportunity to meet with both a physical medicine and rehabilitation doctor and the neurologist together. This was a full body and brain appointment with the doctors collaborating to determine the cause of Leo's delays. One of my favorite lines from one of the doctors was, "We are going to make Leo be the best Leo he can be." That has become my mission as his mom and number-one advocate.

Shortly after that appointment, we began meeting with our school district's resources, including a special ed teacher. It was with this group that I learned how amazing and critical early intervention is for the child and the family. This team of a teacher, physical therapist, and occupational therapist started coming to our home weekly to see Leo and work with us. It was comfortable and helpful to do adaptive work in our home setting that would be realistic for us to continue after they left. We also began seeing a private physical therapist, which led to Leo being fitted with an ankle-foot orthosis on his left leg and foot, and a supramalleolar orthosis on his right foot to help with stability.

What no one could tell me in those early stages of his diagnosis was what to expect for Leo down the road. Would he walk? Would he talk? Would he have any other complications or issues? Looking back, I understand why they couldn't say much with certainty. It would take some time to figure out what impact Leo's brain injury would have on his development. But because the injury occurred as early as it did, Leo had the best possible chance of rewiring his brain to accomplish what he wasn't able to do at that point. With that knowledge, we stuck with the plan of PT and the services from the school.

March is CP Awareness month, and I decided that was the appropriate time to share our story with others. My goal was twofold. First, I didn't want to hide what we were going through because it was a real part of Leo's and our family's story. He was doing well and I was proud of him and us. Second, I knew that sharing could both help others and be a way for us to learn about more resources. It was the right decision: the support we received from everyone was overwhelming. Some shared their own stories with CP or what their children had dealt with and were in the process of overcoming. I was able to gain great perspective and comfort in knowing we weren't alone. Others recommended services and organizations that could help. Those suggestions have turned into critical opportunities for Leo and our family. I'm glad we did share our story and I encourage others to do the same. There is no reason to navigate this road alone.

Leo's journey has mostly been on an upward trajectory. We started Botox injections in his left arm and hand to reduce spasticity, which seemed to work well for him, and it encouraged him to move and keep making progress. He had the injections about every four to six months

for a few years. He accomplished walking at 26 months. He started with a gait trainer to help him build stability and balance, but after some time he ditched it and walked on his own. When he was four and a half, we did serial casting on his left ankle to help him get a better stretch. I had the mentality of "Let's do as much as we can now, early, so that he has a better shot at doing less later." I don't know if my thinking was right, but now that Leo is six, physically bigger and stronger, and understands more, I can say I'm glad we did what we did when he was younger.

There are some difficulties. He has a hard time being at doctors' offices because he understands that there could be something uncomfortable involved. Transitions from one environment to another and being with unfamiliar people can be hurdles for him. We're learning more about how to help him prepare and get through that. The early intervention has been key. We have been so lucky to get help as early as we did. I feel so lucky that we live in a community that has great resources for Leo.

Leo is now a very happy kindergartner even though the adjustment to more structure and expectations has not been easy. He has come a long way with speech, independence, and social skills, but he has a lot still to work on. I hope he will continue to be accepted by his peers, to learn, and to keep his happy disposition as he is faced with the challenges of CP that will never go away. He is more like other kids than he is different. I'm in awe of him every day, knowing how much he has had to overcome to get to this point. I know he is meant to do something great and will continue to make us extremely proud. I'm here to support him, advocate for him, and make Leo the best Leo he can be.

Mark, father of six-year-old Elliot, from London, England

It's difficult to know where to start when talking about such a defining thing in my life. Elliot was born after a very long and tough labor for my partner, Sian. Almost as soon as he was born, the alarm bells started ringing when the nurse noticed that something was wrong, and he was whisked away from us to intensive care.

He was having a series of life-threatening seizures, and the brilliant staff in intensive care worked tirelessly to save him. Eventually, he came through and started to recover, but we didn't know what the cause of the seizures was. Later scans showed that he had had a stroke and that the damage had been extensive, which resulted in him being diagnosed with cerebral palsy. Initially this diagnosis was frightening and hard to take; our minds automatically went to imagining the most severe cases of what can be a devastating disability.

As Elliot developed, it became clear he had a weakness on his left side, and his left hand was largely immobile. We took him to baby classes in the first few months of his life, and I remember the moment so clearly when I noticed that all the other babies in the group were able to sit up unaided, but Elliot still needed support.

We were not given any support or guidance after Elliot was born, but Sian was very driven to find help and funding for him. We worked very hard with him in the early days with standing supports and weekly therapy at a London-based charity for children with cerebral palsy.

Elliot has a real drive to overcome his difficulties and there have been many proud moments—like the first time he walked unaided. Now six years old, he is making us very proud at school by keeping up with his peers. Still, there are many obstacles and difficult moments to overcome. He must wear a splint when walking as he's very unsteady and has frequent falls. He requires one-to-one support at school and has difficulty processing information; he was recently assessed as having a developmental age of a four-year-old.

For me, the most difficult aspect of dealing with Elliot's disability has not been the physical challenges but the difficulties he has with communication and his mood swings we often have to deal with. There is still a lot of uncertainty about his development and whether as an adult he will be able to live independently, but we know the only way to deal with these fears is by living one day at a time and staying focused on the positives.

Elliot has a habit of repeatedly proving us wrong about our deepest held fears. He is a beautiful and engaging little boy and, most encouragingly, he is steadily developing—but at his own pace and on his own terms.

Maria, mother of seven-year-old Sophie, from Ireland

Sophie was born in October 2016. When we got the first indication that Sophie may have suffered a form of brain damage resulting from a brain bleed, I was a little worried, but by no means extremely alarmed. She was 14 months old and such a happy, smiley, bright little thing, so I felt whatever her problems were they would be minor in nature and she would overcome them.

Prior to this, Sophie had missed some important milestones in terms of motor skills and speech, but I had thought that these would come in "their own time" as everyone was advising, and the public health checks and hospital appointments did not note anything out of the ordinary. Looking back, I should have been far more aware, but I suppose that's hindsight. We did not know at the time that Sophie had right hemiplegic cerebral palsy.

After an initial referral by our family doctor to a lovely physiotherapist at the hospital, Sophie was immediately further referred to the neurology team. We will never forget that first appointment when, after having been asked a lot of questions about the pregnancy, we were told by one of the consultant's team that Sophie might not ever walk or talk. We left that appointment devastated, to say the least. We just could not believe what we were being told about our little girl.

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"This book gets my highest recommendation."

—NATHALIE MAITRE, MD, PhD, PARENT

"Wow! This book is the most amazing and comprehensive source of information available for persons with unilateral CP and their families I have ever seen, and it should be required reading for any professionals who care for them."

—DIANE DAMIANO, PhD, FAPTA

"A must-read for all."

—BENJAMIN SHORE, MD, MPH, FRCSC

Spastic hemiplegia is a very common subtype of cerebral palsy (CP), and CP itself is the most common cause of childhood-onset physical disability. An estimated 17 million people worldwide have CP. Spastic hemiplegia is also known as unilateral spastic CP or, simply, unilateral CP.

Spastic hemiplegia affects the upper and lower limbs of one side of the body. The upper limb is usually more affected than the lower limb. This practical guide addresses spastic hemiplegia across the lifespan and the evidence-based, best-practice treatments. It also includes the lived experience of families.

The writing of *Spastic Hemiplegia* was led by Marcie Ward, MD, Pediatric Rehabilitation Medicine Physician at Gillette Children's, a world-renowned center of excellence for the treatment of brain, bone, and movement conditions. *Spastic Hemiplegia* is part of the **Gillette Children's Healthcare Series**, a series of books for families who are looking for clear, comprehensive information. Health care professionals, researchers, educators, students, and extended family members will also benefit from reading *Spastic Hemiplegia*.

Other titles in the series include:

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