

"Every important aspect of
spastic diplegia is addressed."

—H. KERR GRAHAM, MD, FRACS

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Children's
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Series

SPASTIC DIPLEGIA

Bilateral Cerebral Palsy

Second Edition

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

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The title of this book is *Spastic Diplegia—Bilateral Cerebral Palsy*. “Spastic diplegia” is the term historically used to describe this condition, and it remains in use today in the US. The term “spastic diplegia” derives from “spastic” (the type of high tone), “di” (meaning two, referring to the two affected lower limbs), and “plegia” (the Greek word for stroke). Over the past 20 years, the term “bilateral 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. “Bilateral” refers to two sides of the body being affected. The three terms “spastic diplegia,” “bilateral spastic CP,” and “bilateral CP” are all used in the scientific literature. In this book, written in the US, we use the term “spastic diplegia.”

With spastic diplegia, the lower limbs are much more affected than the upper limbs, which frequently show only fine motor impairment. Spasticity is the most common type of atypical tone present, 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, II, and III: those who are capable of walking independently or with an assistive walking device. GMFCS levels I, II, and III account for the majority of individuals with spastic diplegia.

This chapter explains spastic diplegia 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 diplegia in adulthood.

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 spastic diplegia (all GMFCS levels).⁸⁰ See Figure 2.1.2.

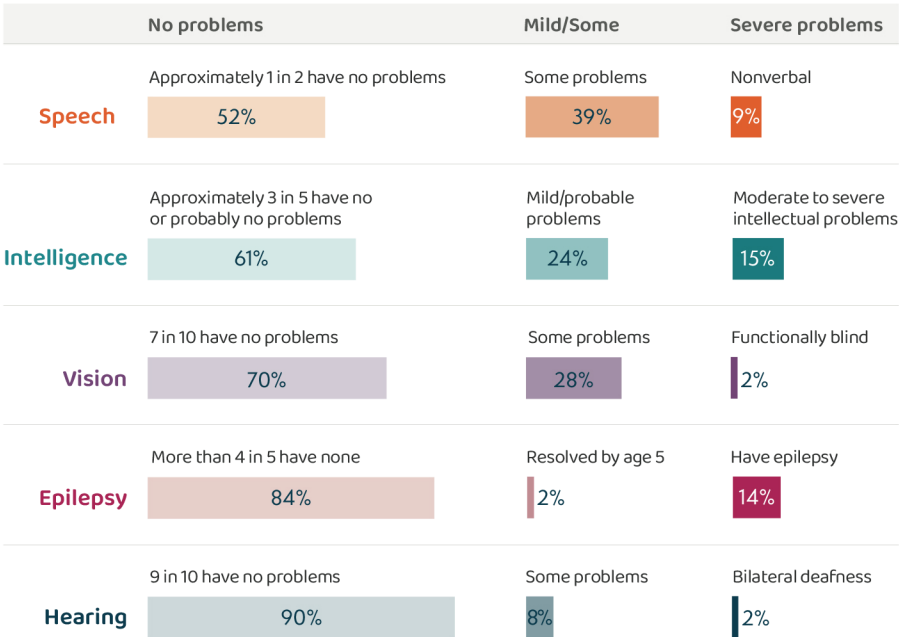


Figure 2.1.2 Prevalence of associated problems among children age five with spastic diplegia (all GMFCS levels).

Figure 2.1.2 shows that a proportion of children with spastic diplegia (all GMFCS levels) have problems in the areas of speech, intelligence (cognition), vision, epilepsy, 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.⁸⁰ 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.⁸⁰ Section 2.10 addresses associated problems in more detail.

Since spastic diplegia affects the lower limbs much more than the upper, this book focuses on the lower limbs and functional mobility for individuals with spastic diplegia.

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 now, almost 30 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.

"A wonderful and thorough book."

—WILMA VAN DER SLOT, MD, PhD

"This book is an indispensable resource."

—MARK D. PETERSON, PhD, MS, PARENT

"I highly recommend this book for both families and clinicians."

—CATHY MORGAN, PhD

Spastic diplegia 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 diplegia is also known as bilateral spastic CP or, simply, bilateral CP.

With spastic diplegia, the lower limbs are much more affected than the upper limbs, which frequently show only fine motor impairment. Now in its second edition, this practical guide addresses spastic diplegia across the lifespan and the evidence-based, best-practice treatments. It also includes the lived experience of families.

The writing of *Spastic Diplegia* was led by Lily Collison, MA, MSc, the parent of a son with spastic diplegia. The first edition of this book gave rise to 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 Diplegia*.

Other titles in the series include:

- *Craniosynostosis*
- *Idiopathic Scoliosis*
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ISBN 978-1-952181-15-3



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