

THE OFFICIAL
PARENT'S SOURCEBOOK

on

CEREBRAL
PALSY



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AND PHILIP M. PARKER, PH.D., EDITORS

ICON Health Publications
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Dedication

To the healthcare professionals dedicating their time and efforts to the study of cerebral palsy.

Acknowledgements

The collective knowledge generated from academic and applied research summarized in various references has been critical in the creation of this sourcebook which is best viewed as a comprehensive compilation and collection of information prepared by various official agencies which directly or indirectly are dedicated to cerebral palsy. All of the *Official Parent's Sourcebooks* draw from various agencies and institutions associated with the United States Department of Health and Human Services, and in particular, the Office of the Secretary of Health and Human Services (OS), the Administration for Children and Families (ACF), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Agency for Toxic Substances and Disease Registry (ATSDR), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Healthcare Financing Administration (HCFA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the institutions of the National Institutes of Health (NIH), the Program Support Center (PSC), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these sources, information gathered from the National Library of Medicine, the United States Patent Office, the European Union, and their related organizations has been invaluable in the creation of this sourcebook. Some of the work represented was financially supported by the Research and Development Committee at INSEAD. This support is gratefully acknowledged. Finally, special thanks are owed to Tiffany LaRochelle for her excellent editorial support.

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INTRODUCTION

Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, “The best prescription is knowledge.”¹ The Agency for Healthcare Research and Quality (AHRQ) of the National Institutes of Health (NIH) echoes this view and recommends that all parents incorporate education into the treatment process. According to the AHRQ:

Finding out more about your [child’s] condition is a good place to start. By contacting groups that support your [child’s] condition, visiting your local library, and searching on the Internet, you can find good information to help guide your decisions for your [child’s] treatment. Some information may be hard to find—especially if you don’t know where to look.²

As the AHRQ mentions, finding the right information is not an obvious task. Though many physicians and public officials had thought that the emergence of the Internet would do much to assist parents in obtaining reliable information, in March 2001 the National Institutes of Health issued the following warning:

The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading.³

¹ Quotation from <http://www.drkoop.com>.

² The Agency for Healthcare Research and Quality (AHRQ):
<http://www.ahrq.gov/consumer/diainfo.htm>.

³ From the NIH, National Cancer Institute (NCI):
<http://cancertrials.nci.nih.gov/beyond/evaluating.html>.

Since the late 1990s, physicians have seen a general increase in parent Internet usage rates. Parents frequently enter their children's doctor's offices with printed Web pages of home remedies in the guise of latest medical research. This scenario is so common that doctors often spend more time dispelling misleading information than guiding children through sound therapies. *The Official Parent's Sourcebook on Cerebral Palsy* has been created for parents who have decided to make education and research an integral part of the treatment process. The pages that follow will tell you where and how to look for information covering virtually all topics related to cerebral palsy, from the essentials to the most advanced areas of research.

The title of this book includes the word "official." This reflects the fact that the sourcebook draws from public, academic, government, and peer-reviewed research. Selected readings from various agencies are reproduced to give you some of the latest official information available to date on cerebral palsy.

Given parents' increasing sophistication in using the Internet, abundant references to reliable Internet-based resources are provided throughout this sourcebook. Where possible, guidance is provided on how to obtain free-of-charge, primary research results as well as more detailed information via the Internet. E-book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned (clicking on a hyperlink automatically opens your browser to the site indicated). Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites. Since we are working with ICON Health Publications, hard copy *Sourcebooks* are frequently updated and printed on demand to ensure that the information provided is current.

In addition to extensive references accessible via the Internet, every chapter presents a "Vocabulary Builder." Many health guides offer glossaries of technical or uncommon terms in an appendix. In editing this sourcebook, we have decided to place a smaller glossary within each chapter that covers terms used in that chapter. Given the technical nature of some chapters, you may need to revisit many sections. Building one's vocabulary of medical terms in such a gradual manner has been shown to improve the learning process.

We must emphasize that no sourcebook on cerebral palsy should affirm that a specific diagnostic procedure or treatment discussed in a research study, patent, or doctoral dissertation is "correct" or your child's best option. This sourcebook is no exception. Each child is unique. Deciding on appropriate

options is always up to parents in consultation with their children's physicians and healthcare providers.

Organization

This sourcebook is organized into three parts. Part I explores basic techniques to researching cerebral palsy (e.g. finding guidelines on diagnosis, treatments, and prognosis), followed by a number of topics, including information on how to get in touch with organizations, associations, or other parent networks dedicated to cerebral palsy. It also gives you sources of information that can help you find a doctor in your local area specializing in treating cerebral palsy. Collectively, the material presented in Part I is a complete primer on basic research topics for cerebral palsy.

Part II moves on to advanced research dedicated to cerebral palsy. Part II is intended for those willing to invest many hours of hard work and study. It is here that we direct you to the latest scientific and applied research on cerebral palsy. When possible, contact names, links via the Internet, and summaries are provided. It is in Part II where the vocabulary process becomes important as authors publishing advanced research frequently use highly specialized language. In general, every attempt is made to recommend "free-to-use" options.

Part III provides appendices of useful background reading covering cerebral palsy or related disorders. The appendices are dedicated to more pragmatic issues facing parents. Accessing materials via medical libraries may be the only option for some parents, so a guide is provided for finding local medical libraries which are open to the public. Part III, therefore, focuses on advice that goes beyond the biological and scientific issues facing children with cerebral palsy and their families.

Scope

While this sourcebook covers cerebral palsy, doctors, research publications, and specialists may refer to your child's condition using a variety of terms. Therefore, you should understand that cerebral palsy is often considered a synonym or a condition closely related to the following:

- Cerebral Diplegia
- Congenital Spastic Paralysis

- Congenital Static Encephalopathy
- Infantile Cerebral Paralysis
- Little Disease
- Little's Disease
- Palsy

In addition to synonyms and related conditions, physicians may refer to cerebral palsy using certain coding systems. The International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) is the most commonly used system of classification for the world's illnesses. Your physician may use this coding system as an administrative or tracking tool. The following classification is commonly used for cerebral palsy:⁴

- 343 infantile cerebral palsy
- 343.9 infantile cerebral palsy, unspecified
- 343.9 infantile cerebral palsy, unspecified

For the purposes of this sourcebook, we have attempted to be as inclusive as possible, looking for official information for all of the synonyms relevant to cerebral palsy. You may find it useful to refer to synonyms when accessing databases or interacting with healthcare professionals and medical librarians.

Moving Forward

Since the 1980s, the world has seen a proliferation of healthcare guides covering most illnesses. Some are written by parents, patients, or their family members. These generally take a layperson's approach to understanding and coping with an illness or disorder. They can be uplifting, encouraging, and highly supportive. Other guides are authored by physicians or other healthcare providers who have a more clinical outlook. Each of these two styles of guide has its purpose and can be quite useful.

As editors, we have chosen a third route. We have chosen to expose you to as many sources of official and peer-reviewed information as practical, for the purpose of educating you about basic and advanced knowledge as

⁴ This list is based on the official version of the World Health Organization's 9th Revision, International Classification of Diseases (ICD-9). According to the National Technical Information Service, "ICD-9CM extensions, interpretations, modifications, addenda, or errata other than those approved by the U.S. Public Health Service and the Health Care Financing Administration are not to be considered official and should not be utilized. Continuous maintenance of the ICD-9-CM is the responsibility of the federal government."

recognized by medical science today. You can think of this sourcebook as your personal Internet age reference librarian.

Why “Internet age”? When their child has been diagnosed with cerebral palsy, parents will often log on to the Internet, type words into a search engine, and receive several Web site listings which are mostly irrelevant or redundant. Parents are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with cerebral palsy is even indexed in search engines, a non-systematic approach often leads to frustration and disappointment. With this sourcebook, we hope to direct you to the information you need that you would not likely find using popular Web directories. Beyond Web listings, in many cases we will reproduce brief summaries or abstracts of available reference materials. These abstracts often contain distilled information on topics of discussion.

While we focus on the more scientific aspects of cerebral palsy, there is, of course, the emotional side to consider. Later in the sourcebook, we provide a chapter dedicated to helping you find parent groups and associations that can provide additional support beyond research produced by medical science. We hope that the choices we have made give you and your child the most options in moving forward. In this way, we wish you the best in your efforts to incorporate this educational approach into your child’s treatment plan.

The Editors

PART I: THE ESSENTIALS

ABOUT PART I

Part I has been edited to give you access to what we feel are “the essentials” on cerebral palsy. The essentials typically include a definition or description of the condition, a discussion of who it affects, the signs or symptoms, tests or diagnostic procedures, and treatments for disease. Your child’s doctor or healthcare provider may have already explained the essentials of cerebral palsy to you or even given you a pamphlet or brochure describing the condition. Now you are searching for more in-depth information. As editors, we have decided, nevertheless, to include a discussion on where to find essential information that can complement what the doctor has already told you. In this section we recommend a process, not a particular Web site or reference book. The process ensures that, as you search the Web, you gain background information in such a way as to maximize your understanding.

CHAPTER 1. THE ESSENTIALS ON CEREBRAL PALSY: GUIDELINES

Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on cerebral palsy. These are typically called “Fact Sheets” or “Guidelines.” They can take the form of a brochure, information kit, pamphlet, or flyer. Often they are only a few pages in length. The great advantage of guidelines over other sources is that they are often written with the parent in mind. Since new guidelines on cerebral palsy can appear at any moment and be published by a number of sources, the best approach to finding guidelines is to systematically scan the Internet-based services that post them.

The National Institutes of Health (NIH)⁵

The National Institutes of Health (NIH) is the first place to search for relatively current guidelines and fact sheets on cerebral palsy. Originally founded in 1887, the NIH is one of the world’s foremost medical research centers and the federal focal point for medical research in the United States. At any given time, the NIH supports some 35,000 research grants at universities, medical schools, and other research and training institutions, both nationally and internationally. The rosters of those who have conducted research or who have received NIH support over the years include the world’s most illustrious scientists and physicians. Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

⁵ Adapted from the NIH: <http://www.nih.gov/about/NIHoverview.html>.

There is no guarantee that any one Institute will have a guideline on a specific medical condition, though the National Institutes of Health collectively publish over 600 guidelines for both common and rare disorders. The best way to access NIH guidelines is via the Internet. Although the NIH is organized into many different Institutes and Offices, the following is a list of key Web sites where you are most likely to find NIH clinical guidelines and publications dealing with cerebral palsy and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at <http://www.nih.gov/health/consumer/conkey.htm>
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines available at <http://www.nlm.nih.gov/medlineplus/healthtopics.html>
- National Institute of Neurological Disorders and Stroke (NINDS); http://www.ninds.nih.gov/health_and_medical/disorder_index.htm

Among the above, the National Institute of Neurological Disorders and Stroke (NINDS) is particularly noteworthy. The mission of the NINDS is to reduce the burden of neurological disease—a burden borne by every age group, by every segment of society, by people all over the world.⁶ To support this mission, the NINDS conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas. The following patient guideline was recently published by the NINDS on cerebral palsy.

What Is Cerebral Palsy?⁷

In the 1860s, an English surgeon named William Little wrote the first medical descriptions of a puzzling disorder that struck children in the first years of life, causing stiff, spastic muscles in their legs and, to a lesser degree, their arms. These children had difficulty grasping objects, crawling, and walking. They did not get better as they grew up nor did they become worse. Their condition, which was called Little's disease for many years, is now known as spastic diplegia. It is just one of several disorders that affect

⁶ This paragraph has been adapted from the NINDS:

http://www.ninds.nih.gov/about_ninds/mission.htm. "Adapted" signifies that a passage has been reproduced exactly or slightly edited for this book.

⁷ Adapted from The National Institute of Neurological Disorders and Stroke (NINDS): http://www.ninds.nih.gov/health_and_medical/pubs/cerebral_palsyhtr.htm.