In the early 1990s, when he began his study of its causes and effects, Professor Robert Goodman described childhood hemiplegia as a ‘Cinderella’ condition. As recently as 2007 HemiHelp, the UK charity that provides support and information to people affected by the condition, had a letter from a man in his thirties who had only just discovered that he had hemiplegia while seeing his family doctor about something else. Even when it was diagnosed, hemiplegia was usually thought of as a mild physical disability, and families were left to get on with it with little or no support. And this was despite the fact that hemiplegia is quite a common condition, affecting about one child in a 1000.

Thankfully, things have moved on. Awareness of hemiplegia (also known as hemiparesis or hemiplegic cerebral palsy) in the medical professions has grown, and work by researchers around the world is adding to our knowledge of the condition. In particular, thanks to studies by Professor Goodman and others, people are much more aware that hemiplegia is not just a question of a weak arm and leg with, for some children, a few ‘associated conditions’, as they were referred to at the time, such as epilepsy, perhaps, or difficulties with some subjects at school. We now recognize it as a complex condition in which these hidden difficulties are not only more common than was realized previously but often have a more serious effect on the child’s life than the more obvious ones. In other words, with hemiplegia what you see is not what you get. It is not surprising that parents, in the early years, and later on the young people themselves, find themselves constantly having to explain hemiplegia to the world at large.

But now at least they have rather more sources of information to refer to. In 1990 a handful of parents whose children had taken part in Professor Goodman’s study set up HemiHelp as a support group to try to help others in the same situation. My son was too young to be included in the study, but I joined the group a year or so later. Since then I’ve been closely involved in writing and editing HemiHelp’s information.
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materials, which cover a wide range of practical issues from bikes to benefits and from shoelaces to Statements of Special Educational Needs. HemiHelp members tell us that they find these very helpful, especially now that they can be downloaded from the charity’s website. However, I have felt for many years that it would be useful to have a book that would give a fuller picture of hemiplegia, its causes and effects and how to get on with living with it – whether you are a person with the condition, a family member, or a teacher or other professional working with children with hemiplegia. And now it has happened. This is in fact the second book on the subject to be published in the UK, but the first, *Congenital Hemiplegia,* is aimed at medical professionals and can be a hard read for anyone else.

Of course, no book can tell the reader everything, but my co-author, Dr Charlie Fairhurst, and I have tried to cover all the main areas. As part of the preparation for writing this handbook, HemiHelp carried out a survey of its parent members, and asked them, among other things, what they would like to see in it. About a quarter of parent members completed the survey, and from their answers it became clear that it was important for parents to know as much as possible about their child's condition, as the more they knew, the better prepared they would be to fight for the best possible help and support for him or her.

Each chapter of this handbook covers one subject, broken down into sections on different aspects and how they relate to children of different ages, from babies to teenagers and beyond. So parents, teachers and other professionals can dip into the handbook again and again as a child grows and their needs change. They will also find contact details for the many organizations that can provide more information, or help with complex matters such as applying for financial benefits or getting a Statement of Special Educational Needs. There are references, too, to information sheets, downloadable from the HemiHelp website (www.hemihelp.org.uk/hemiplegia/publications/leaflets/), that cover individual topics in greater detail than there is space for here. And, since one of the most valuable things that people can have as they meet the challenges of living with hemiplegia is other people’s personal experience, we have also included stories and suggestions from parents, as well as young people and adults who have grown up with the condition. Many thanks to all of them for their contribution, and to everyone who completed the survey as well as parents who sent us photographs to illustrate the book.

Most childhood hemiplegia is what is known as *congenital* (in other words, it developed before or around the time of the child’s birth), so much of the handbook assumes that this is the kind of hemiplegia we are talking about. Of HemiHelp family members, 80% have a child whose condition is congenital; the other 20% have a child who ‘acquired’ his or her hemiplegia later in childhood as the result of an accident or illness, and we have included a section on *acquired hemiplegia,* as this is known (see Chapter 4). However, most of the information contained in the handbook is equally useful for both types.

Although there are children with hemiplegia in every country, approaches to treatment and provision of services differ around the world, and for want of space we have had to aim this handbook mainly at readers in the UK. Even here, although health, social and education services are broadly similar throughout the UK, there are local differences in both how they are organized and what they are called, and we have tried to reflect this in the relevant chapters.

This handbook is also coming out at a time when significant changes are planned for the National Health Service, the benefits system and the support our children will receive during their education. So some of what is written here may be out of date before you read it. For this reason we have set up a dedicated page on the HemiHelp website for corrections and updates, and refer our readers to this in the relevant sections.

A word about labels: medical professionals use a number of names when they diagnose this condition: hemiplegia, hemiparesis, ‘hemiplegic cerebral palsy’ or sometimes just cerebral palsy. Many parents are unhappy about using this last name, especially if their child’s hemiplegia seems mild. Others find it useful as a label because everyone has heard of it – I have sometimes said that my son has a sort of mild cerebral palsy, or talked about him having had a sort of stroke before he was born. Likewise, some parents are content to use the words ‘disabled’ and ‘disability’ when talking about their child, others not. Obviously this may depend on how mild or severe the hemiplegia seems. But, as parents, we can sometimes find ourselves using a word we would rather not use, either because it is easier to understand or because it seems useful at the time. When my son was diagnosed, his hemiplegia seemed fairly mild and mainly affected his arm, and when he went to a local mainstream playgroup I told just them that he had something called hemiplegia, which made his right arm and hand weak. Then, when he was about three and a half and ready for a primary school nursery class, I discovered that the school I had chosen had lost his application. The head teacher told me that they had no places left at nursery, and I knew that the same would be true of other local schools. I realized that I had one card up my sleeve, took a deep breath and said, ‘Well actually he has a mild disability and I think he needs to have time in nursery to get used to the hustle and bustle of school before reception class.’ I have never seen anyone’s ears prick up like that before or since – within a week he had a place. Since then I have realized that, sometimes, if we want help for our children, we have to use whatever means we can, and it is difficult to avoid using labels such as ‘disability’ or ‘cerebral palsy’. In the same way, a Statement of Special Educational Needs should be seen as an opportunity to get more help, not as a punishment. Remember that these are just labels and your child is always your child.
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Bringing up any child is a voyage into the unknown – bringing up a child with a disability or additional needs even more so. The road ahead is less predictable, the challenges and obstacles greater, the anxieties deeper. But you need to remember that your child with hemiplegia is, first and foremost, a child like any other, and can grow up to lead a happy, useful adult life. We hope that this handbook will help you on your journey.

Note: All website information sheets, booklets etc., mentioned in this book are downloadable for free unless otherwise stated. References in this book to parents also apply to carers.