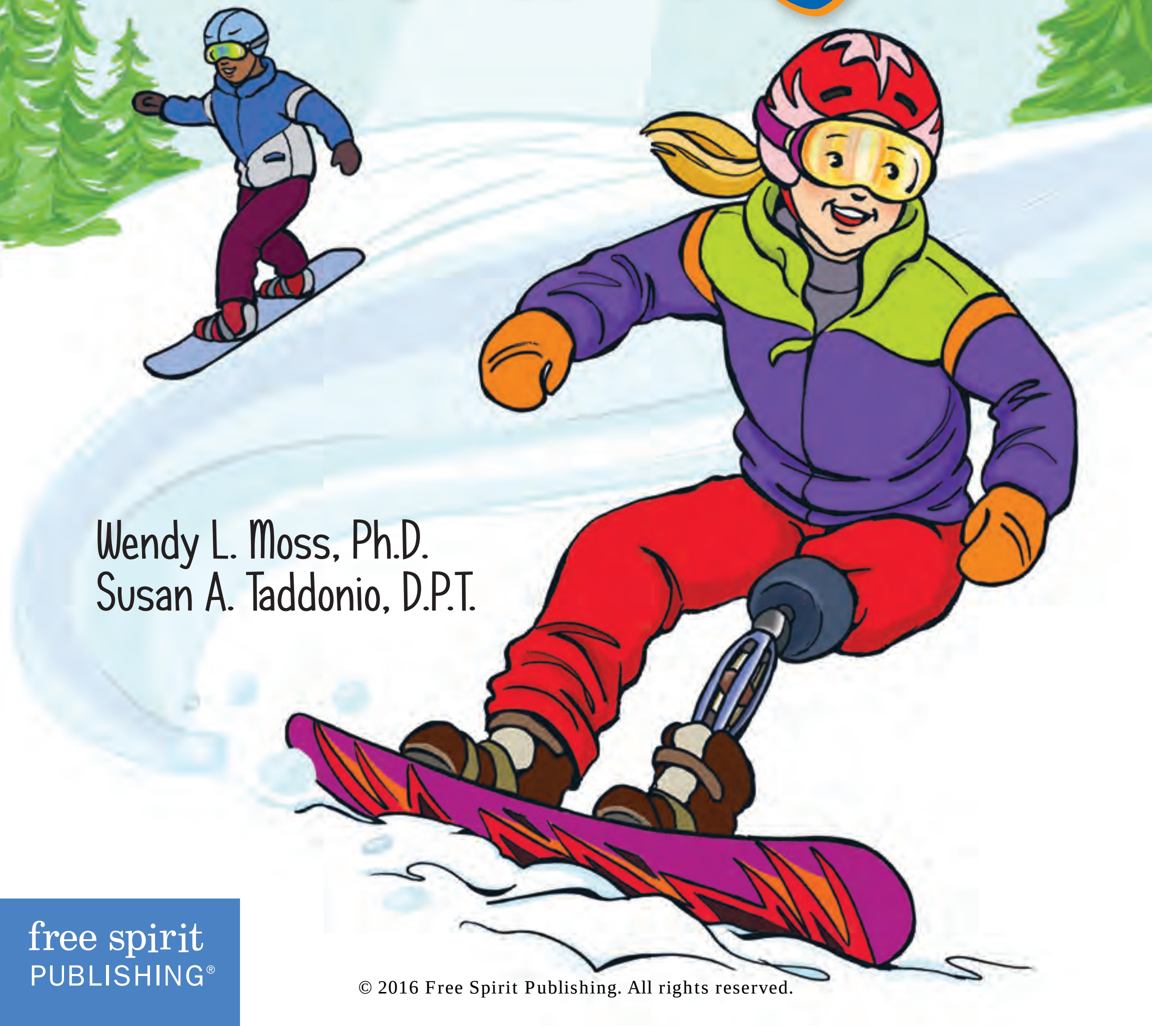
THE SURVIVAL GUIDE FOR

Kids with Physical Disabilities & Challenges



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To Kenneth Moss, a man who doesn’t judge a book by its cover and looks for the silver lining in each cloud. He celebrates the good in others, and I celebrate having him in my life!—W.M.

To Cody, my son, whose empathy, honesty, and sense of humor have impacted so many, and to Alexus, my daughter, who is brilliant and determined, who is the strongest woman, and who will one day change the world!—S.T.

Contents

Introduction

Coping with Your Challenge

- Do you ever feel different and alone?
- Do you ever wonder what other kids with physical disabilities or difficulties feel?
- Do you wonder what they do to overcome problems and obstacles?
- Do you sometimes feel jealous of kids who don't have physical challenges?
- Do you sometimes wish you didn't have to do your therapy exercises?
- Does your physical issue make you feel sad, angry, frustrated, or scared?
- Do you worry about the future?

If you answered yes to any of these questions, **this book is for you!**

How This Book Can Help You

Since you are reading this book, you probably have a physical disability or challenge. You might have a long-term physical difficulty. Or maybe you have a chronic illness or a serious medical concern. Whatever your condition, you may find that you face challenges other kids don't have to deal with. And we're not just talking about your physical challenges. At times, a physical issue can lead to feeling misunderstood. Some kids become unhappy with how they see themselves. And some feel like nobody else knows what it's like to be in their shoes.

Of course, nobody can know exactly what it's like to be you. But the truth is, **you are not alone.** Lots of kids deal with physical issues just like you do. And they face lots of the same questions and problems. You'll meet a bunch of these kids in this book. We have worked with hundreds of young people who have struggled with physical differences or illnesses. That includes kids with physical challenges like cerebral palsy, seizures, spina bifida, rheumatoid arthritis, amputations, and Crohn's disease. Their stories are the heart of this book. We have changed names and combined the details about many individuals, but the struggles and successes are real. Even if you don't see anyone here who has the exact same physical issue as you, you will probably find that you face similar concerns and challenges.

"I never talked to anyone else who shared their feelings about having a disability. None of my friends have one. My friends are great and they try to understand me. Still, I wish I had a chance to find out how another kid deals with having a disability and getting through each day."—Alexander, age 11

Reading this book may help you feel less alone. It will also give you lots of ideas for feeling more positive and managing your physical issues. It can help you get along better with your family and friends. You'll find ideas for helping others understand you and learn how to help and support you.

Kids live in all kinds of families. When you read about *parents* in this book, think of the adult or adults who live with and take care of you. This might be your dad, mom, stepparent, foster parents, guardians, or adult relatives.

How to Use This Book

It can be really helpful to read this book with your parents and discuss it with them. If you prefer, feel free to read it by yourself. Just be sure to talk about what you read with your mom, dad, or another adult you trust.

You can read this book straight through or skip around. That's up to you. You'll probably get the most benefit if you read all of it. But if there's something you want help with right now, look it up in the index or check out these chapter summaries:

Chapter 1: Who Are You . . . Really? Here, you can look at how you see yourself and who you really are—beyond your medical or physical problem.

Chapter 2: Helping Other Kids Understand You. Discover strategies for teaching kids around you about the total package that is you!

Chapter 3: Working with Your Support Team. Learn about many of the specialists who help kids with physical differences and disabilities. Some of these people are probably part of your support team. You'll find out how you can become an active member in that team. You'll also learn how to be part of the process of selecting specialists for your team.

Chapter 4: Getting and Staying Motivated. This chapter is loaded with tips for getting and staying focused as you work with your support team and set goals. You'll find out how to get started, keep working, and believe in yourself.

Chapter 5: Staying Positive (When You Just Can't Seem to Smile). Do you sometimes struggle with sadness or other negative feelings? Lots of kids do. That includes fears about the future. Chapter 5 has some important tools that can help you.

Chapter 6: Becoming More Independent. This chapter explores ways to take control and create more choices in your life.

Chapter 7: Getting the Most Out of School (And Thinking About Your Future). This chapter can help you start to plan for your next school year, future school years, and even your job choices later on.

In all of the chapters, you'll find quotes from kids and stories about kids. You'll find lots of tips and ideas to try in boxes labeled "Try This." Sections labeled "You Can Say" give you examples of how to talk about things that might seem tricky. Often, we suggest that you write down ideas or make a list of things to remember. You can do this with pen and paper, use a dictation device (like a computer program), or type into a computer—whatever method works best for you. You might want to keep a notebook so all your ideas are together. Then you can refer to them easily.

At the end of the book is a **Note to Parents** that you can show to your mom or dad. You can also read the Note to Parents if you're curious.

Why We Wrote This Book

We have spent decades working with kids. Many of these kids have physical challenges or other disabilities. A lot of them have told us about feeling misunderstood and different. Many are curious about how other kids deal with a challenge like theirs. We have been honored to be a part of their support teams. We wrote this book so that you can learn from the challenges and successes of others and benefit from our experiences in helping kids.

The main thing we hope you take away from the book is this: **Your physical issues are not who you are.** They are just a part of you. It's true that they can cause struggles in your life, but being creative can help you work around them. This book has lots of ways to help you cope with challenges that you face emotionally, socially, and physically.

We hope the book helps you, and we wish you all the best!

Wendy L. Moss, Ph.D.
Susan A. Taddonio, D.P.T.

Chapter 1

Who Are You . . . Really?

It seems like a simple question. Who are you? You can answer by giving your name, your age, the color of your hair, and your height. You can answer by explaining your physical difficulties.

But do those things really define **YOU?**

Every person is a unique individual. It's important to know who you are—inside—so you can focus on your strengths, work on your challenges, and let others know all about your positive qualities. If you focus more on your *abilities* than your disabilities, you're likely to feel better about yourself. You'll be more confident, too, and enjoy life more.

You Are Not Your Disability

Unless you're reading this book to help someone else, you probably have a physical challenge. You may struggle with how your legs or arms work, or with your ability to speak clearly. You might have trouble with your coordination or with controlling body functions (like breathing or toileting). Or maybe you have other difficulties. Even someone who has *all* of these issues would also have many things that make that person special in a positive way. **You are much more interesting and complicated than what your body can or can't do.**

Check out how Stacey describes herself.

> "I'm a tall 10-year-old girl and I walk a little funny. I have a problem called spina bifida. I have to get physical therapy. I wish I could walk better, but I have to keep trying. I sometimes feel my legs get tired."
> —Stacey, age 10

Does that description tell you anything about Stacey's talents? Her sense of humor? What she does for fun? What else could she talk about that describes who she really is?

Your disability or challenge is a part of what you have to deal with in life—probably a big part. It may cause you frustration, or even some pride in how you overcome it. It's natural to think of it as part of who you are.

Still, it is only one aspect of your identity. You also have your own way of thinking. You have your own personality, sense of humor, choice of friends, and interests. You probably like certain subjects in school more than others. You act in certain ways when around other kids. All of these things make up the real you. No one picks friends just because of how their arms or legs work. They pick friends for much more personal reasons: who they are.

Describe Yourself

So, who are you? Here are some words that describe positive traits that many kids have. Do any of them fit you?

funny
caring
honest
friendly
happy
smart
loyal
creative
trustworthy
calm
down-to-earth
optimistic
enthusiastic
reliable
capable
kind
courageous
determined
fun-loving
interesting
respectful
thoughtful
responsible
clever

Other things can help describe you, too, like:

- your interests and hobbies
- the activities you're involved in
- your favorite TV shows and websites
- the music or comedians you listen to
- books and video games you like

A description of you can contain all of these ideas, or some of them, or other ideas.

Even though it's healthy to focus mostly on who you are on the inside, the challenges we all face—like physical disabilities—shape who we are as well. They give us opportunities to learn, grow, and change. How have your physical challenges shaped you? What have you learned from your disability? Have you learned to overcome challenges? Face difficult times? Work hard? Focus on these abilities that you have gained along with your other strengths.

Try This

Write, dictate, or type a few sentences that explain who you are. Think about what you have already learned in this chapter.

- What words describe your personality?
- What do you like to do in and outside of school?
- What have you learned from your disability?

Write as little or as much as you like. If you aren't sure how to get started, ask a trusted adult, such as a parent, to help you.

Once you have written down some ideas about yourself, remember to share this information with others so they understand who you are. For example, you can teach others about who you are by how you act and by telling them about your interests. You might look at your list of ideas before you meet new people. Some kids find that it helps to write a letter to their teachers so that teachers can understand them better.

MALIK

Malik is an 11-year-old boy who just transferred to a new middle school. He wanted his teachers to know that he has cerebral palsy (CP) and can't always walk fast enough to get to class before the bell rings. He also wanted them to know that he tries hard but his hand isn't always strong enough for him to write for long periods of time. His dad reminded him to tell the teachers about his personality and strengths, too.

Malik sent emails to each of his teachers and briefly described himself. Here is what he wrote:

"My name is Malik. I am new to the school and don't know my way around. I know I'll learn how to get around the building, but sometimes it may take me longer to get to your class. I have cerebral palsy (CP) and my legs and arms don't always work the right way. I try hard, though. Really hard. I also like to laugh and I like to have fun. I love the Horrible Histories books because they combine my love of history and humor. Have you read any of those?

"I have a hard time making friends. I think sometimes other kids are scared of me because I wear leg braces, move awkwardly, and don't play sports. Some of them

think I'm weird until they get to know me. Can you help me with this?

"Oh, I almost forgot. I also care about schoolwork. I think I'm pretty smart, and I don't lie. Nothing really scares me, and I've had to deal with some pretty tough stuff, like hospitals and physical therapy. Thanks for reading this."

When Malik sent this email to his teachers, they learned a lot about him, including his willingness to discuss his physical disability, his desire to fit in, and some things about his personality. The teachers got a better idea of how to help Malik. And writing the letter helped Malik learn more about himself.

Writing to your teachers can be helpful even if you have been in their classes or in the school for a while. An easy way to do this is with email, but you can also write notes and leave them in the teachers' mailboxes at school. You can even just set up a time to talk. The more your teachers learn about who you are, the easier it will be for them to understand you.

Are You Happy with Your View of Yourself?

As you think about how you see yourself, think about how well you like that image. **Are there things you wish you could change?** If so, is it possible to change them? You can change certain things about yourself—like how you treat friends, how you do in school, how you spend your free time, and so on. Other things you can't change, of course. You're stuck with your eyes, ears, and most other physical features, whether you love them or not.

When it comes to your physical challenges, can you change how your body works? Yes and no. Here's an example: You might not be able to change the fact that you are in a wheelchair. However, you might be able to find ways to be less limited by it. For instance, if you have strong arms, maybe you can put a special bag on the side of the wheelchair and take things out of it when you need them. That way you won't have to rely on others to carry your backpack from class to class. This may give you a greater sense of independence.

Working hard at therapy can help change what you can do, too. Chapter 3 talks about people on your support team—your doctor or physical therapist (or even occupational therapist, speech therapist, or pulmonologist). Asking these people questions will help you learn more specific information about what you can physically control and what you can't.

Here's some really important news: **You can even control many of your thoughts and feelings so that you feel better about yourself.**

Maybe you sometimes get down about your physical needs and difficulties. Or you feel it's unfair that you have to stretch or practice exercises when many other kids don't have to work so hard.

If you have strong negative feelings like anger or sadness, try to find ways to focus more on the positive. One thing you might do is think of your exercises as a step toward reaching your goals. Maybe you can exercise with others who have similar issues so it becomes a social time for you. Or turn on your favorite music so you get to enjoy the songs and don't focus as much on the discomfort.

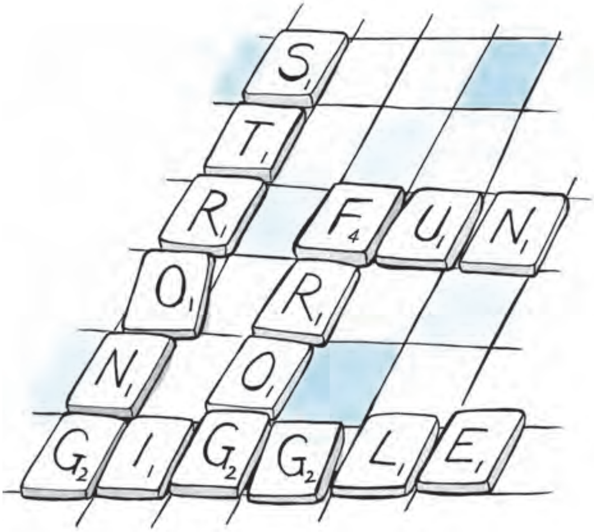
As you do your work, remind yourself that you can **feel proud of yourself for trying your best.** It can be tough to do all the exercises your therapists recommend, especially if you feel that your friends who don't have physical difficulties could succeed at the exercises easily. Give yourself compliments for rising to these challenges.

LATISHA

Latisha was a 10-year-old girl with muscular dystrophy. Her doctors told her that her condition may get worse over time. They told her that it was hard to know for sure, since every case was different. Her main issue was that her legs felt weak and tight.

Latisha was mad at the world and jealous of everyone who didn't have this problem. She cried a lot and refused to hang out with other kids, even though she had some friends in school. But then she saw a psychologist who reminded her that she had a lot of choices in her life. She could be depressed, stop exercising, and be resentful of others who didn't have muscular dystrophy. Or she could work to feel better.

Latisha, her psychologist, and her mom came up with a plan to help her feel a little better each day. First, her mom helped her make a list of her positive qualities and strengths so she could focus on those things. The list was long and had things like Latisha's sense of humor, her excellent reading and writing skills, and her skill at taking care of animals. Next, Latisha decided to stop avoiding other kids. She asked the principal if she could occasionally play board games outside at recess. The principal agreed, and Latisha began to take a magnetic Scrabble game to school. Before long, she had a group of friends who wanted to play with her. Soon after that, Latisha began to hang out with kids on weekends, too.



Latisha also continued talking with her psychologist and other therapists to find ways to enjoy herself more. Over time, she began to feel better. "I'm going to fight my muscular dystrophy every step of the way," she told her mom. "Maybe I won't beat it, but I'm going to have fun each day and not give up."

Try This

Here are some tips to help you focus on the positive.

1. Focus on what you **can** do.
2. Spend time with close friends and supportive adults who accept you for you.
3. Keep busy with activities you enjoy.
4. Change negative thoughts into more positive ones, like this:
    - Negative thought: "I hate my body."
    - Positive thought: "Even though I don't like that my right arm is too weak to use much, I've learned ways to do a lot of things I enjoy. And I have good friends who are happy to help me when I need it."
5. Communicate well with your therapists. Share your goals and frustrations. Let them know which exercises hurt a lot or help a lot. Ask their advice on problems you face. They are trained to help.
6. Give yourself rewards for putting in effort!

Sometimes community activities that your classmates are involved in could help you or just be fun for you. For instance, consider joining your library's book club for kids. Or join a swimming program at a local YMCA. Perhaps there's a group for kids who have physical disabilities where, together, everyone can brainstorm ways to cope.