

# Right Under My Nose



**A Book for  
Children with Spina Bifida**

 **Claire Austin, MPhil  
and Stacey Mizokawa, PhD  
Illustrated by Matthew Bates**

# Right Under My Nose

A Book for Children with Spina Bifida

By Claire Austin, MPhil  
and Stacey Mizokawa, PhD

Illustrated by Matthew Bates



CA: To my family, and the real Eddie.

SM: To my son Andrew, and all the children who have enriched my life.

MB: To my family, Toonacious Family Entertainment, and all the children whose lives this book will touch.



## ACKNOWLEDGMENTS

We are profoundly grateful to the staff of the USC University Center for Excellence in Developmental Disabilities (UCEDD) Learning and Growing Together Project and the Childrens Hospital Los Angeles Spina Bifida Program: Amber Fitchew, MPT; Fran Goldfarb, MA, CHES; Hisela Guardado, OTR/L; Monique Hering, PsyD; Justin Kennerly, PT; Liliana Ramirez; Suzanne Roberts, MD; Hoda Sapir, MSW; Michelle Sepulveda; Kristine Tanita, OTR/L; Umme Salma Vahanvaty, MS, RD; and Carrie Ward, BA, for their professional expertise and guidance.

We would also like to extend our thanks to: Robert A Jacobs, MD who provided the foundation to create this new resource for children with spina bifida; Ana Quiran for exceptional project coordination; Olivia Barham for gifted story consultancy; Veronica Torres, RN for superb administrative assistance; and Carley Butler, Edward Flores and Bess Hopper-Moore for sharing their personal experience and time. Last, but certainly not least, we would like to acknowledge the playful genius of Matthew Bates.

We are especially grateful to Evelyn V Martinez, Ceping Chao, Nancy Fareed and Victor Abalos of First 5 LA for their vision and support to make this book available, both in print and online.

CLAIRE AUSTIN, MPhil  
Children's Bibliotherapist  
Childrens Hospital Los Angeles

STACEY MIZOKAWA, PhD  
Psychologist, USC UCEDD  
Project Director, Learning and Growing Together Project  
Childrens Hospital Los Angeles Spina Bifida Program

## INTRODUCTION

This book is designed to help young children with spina bifida understand their condition and discover new ways to enrich their lives.

Parents and caregivers often wonder when and how to talk about sensitive issues with their child. This book provides you with just such an opportunity.

Challenges facing young children with spina bifida include their movement, bathroom routines, exercise needs, diet and scars. *Right Under My Nose* addresses these topics through 3 sections: a story, activity pages for your child to complete and tips pages. Through a novel design, these resources are interrelated to help you talk about what may be sensitive issues for your child.

The story demonstrates a young child with spina bifida leading a full life with zest, dreams, challenges and independence. It also promotes self-advocacy in children with disabilities.

The activity pages personalize the book for your child. The completed, “ready framed” pages can be detached and hung under the sign “[Your Child’s Name] Gallery.” Creating such an art gallery can help build your child’s confidence in talking about spina bifida.

The tips pages offer child-friendly answers to frequently asked questions and activity suggestions. As, or after, your child completes and colors an activity page you can use related material from the tips pages to open and guide discussion about spina bifida. This can help your child ask questions he is afraid to ask; gain understanding and hope; and realize he is not alone.

By talking to your child about spina bifida, and addressing her natural curiosity and concerns, you, your family, and your child can develop a healthy view of the condition and create new possibilities in your lives.



Eddie was born with spina bifida.  
He can't walk very well, so he uses a wheelchair  
and a walker to move around.



But that doesn't stop Eddie!







Eddie is always thinking of fun ways to do things.



And Eddie's best friend, Biff, does *everything* with him.



Biff even goes to school, tucked inside Eddie's backpack.  
One day, Eddie's teacher said,  
"Don't forget to bring something special on Monday, Eddie.  
It's your turn to share at circle time."



Eddie was very excited.

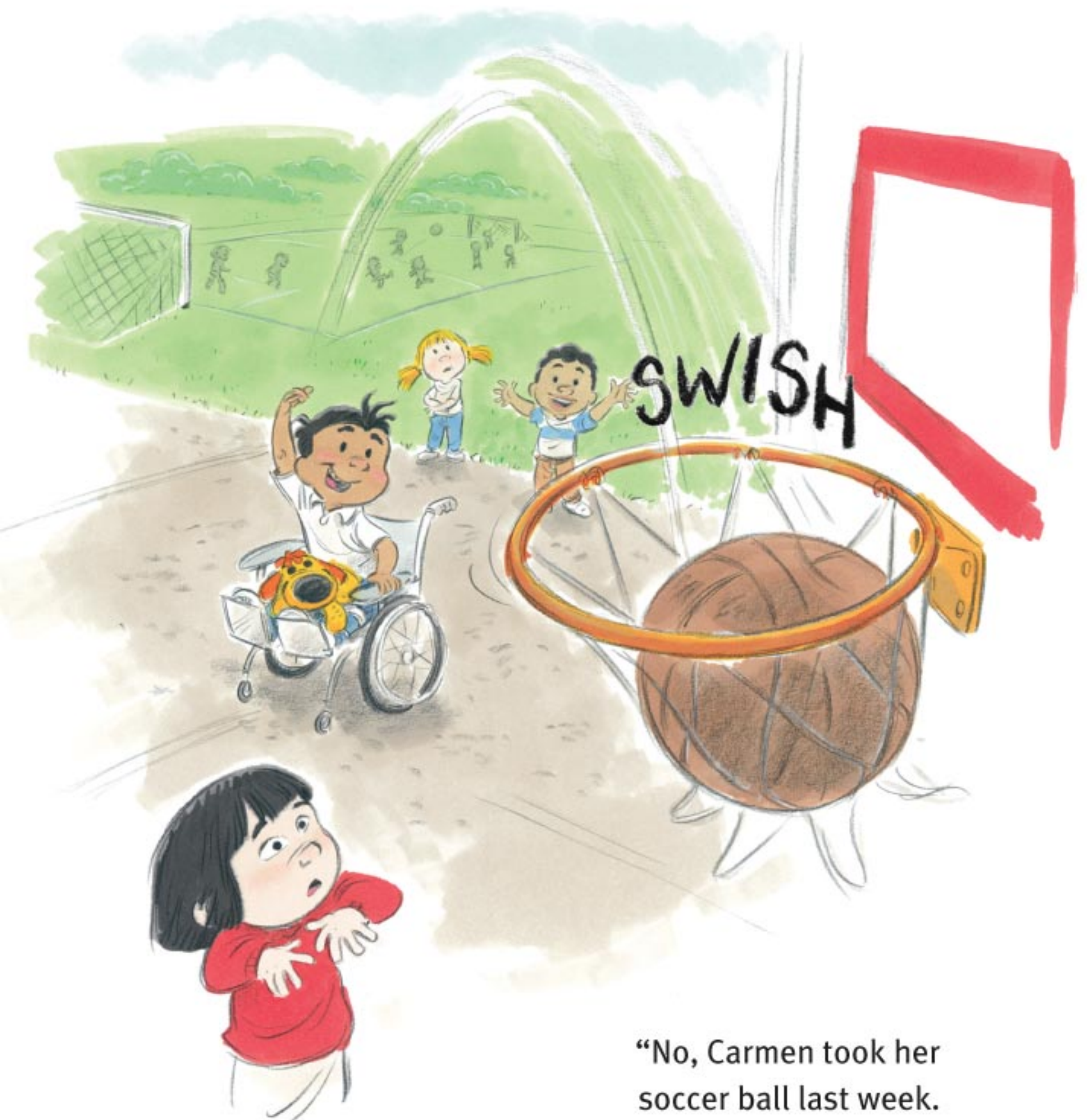
The next day, Eddie got up early to look for something special. “Maybe I could take my dinosaur toothbrush?” he thought.



“No, everyone’s got a toothbrush.  
That’s not special.”

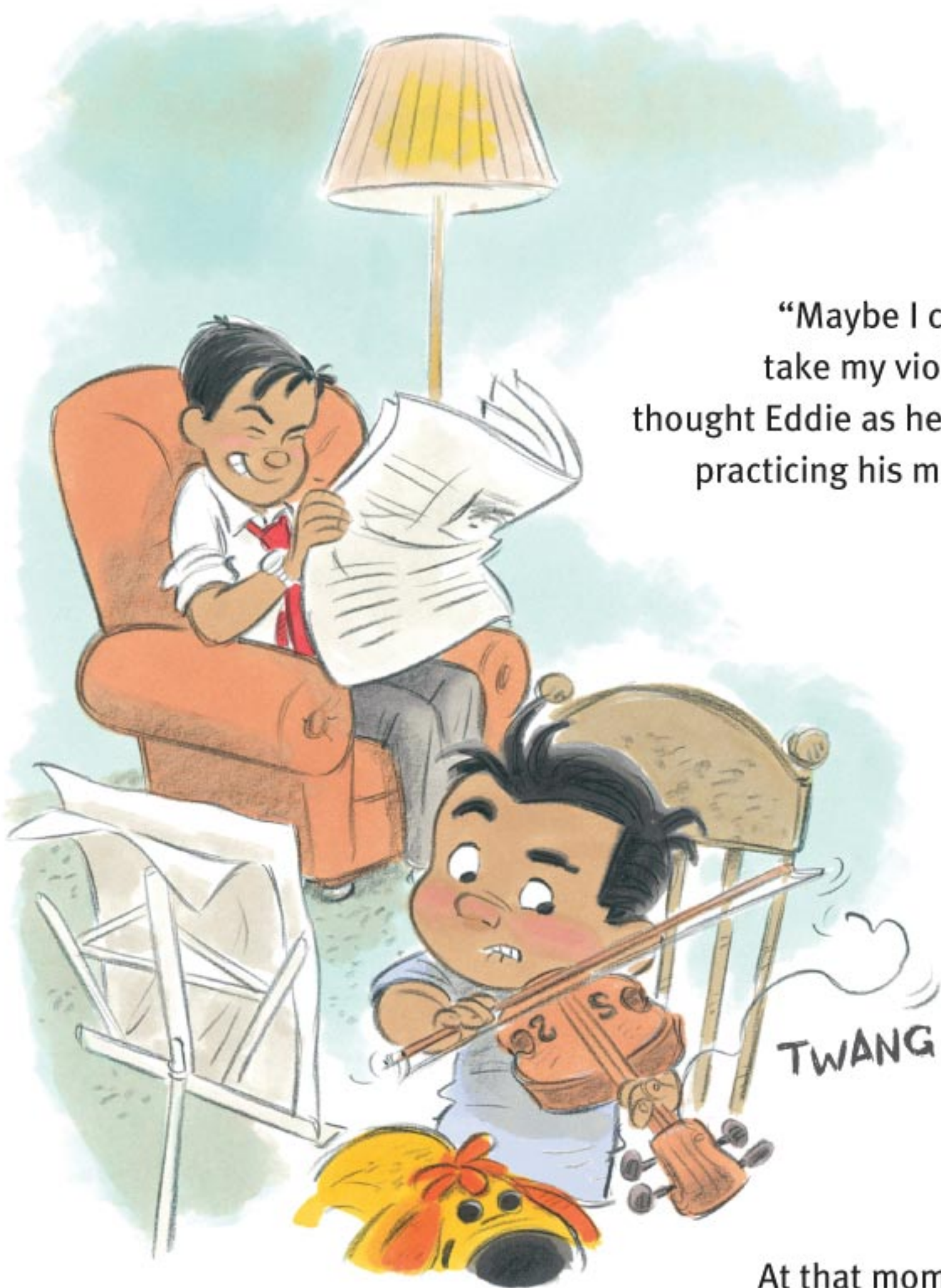


While he was playing with his friends, Eddie thought,  
“Maybe I could take my basketball?”



“No, Carmen took her  
soccer ball last week.  
That’s not special.”





“Maybe I could  
take my violin?”  
thought Eddie as he was  
practicing his music.

At that moment,  
one of the strings broke.  
“No, maybe not.”



When Eddie did his stretching exercise,  
he thought of more things  
he could take.



But nothing was *really* special.

“Mom, I can’t find anything to take for circle time.”



“Perhaps you’re looking too hard,” said Mom.

“Sometimes what you’re looking for  
is right under your nose.”



That night, as Eddie lay in bed,  
he thought about what his mom had said.



“Right under my nose.  
Something special is right under my nose.”



“I know!  
Biff!  
You’re special.  
I’ll take you to school!”



The next morning, as Eddie was changing his diaper, he told his mom the good news.



“Mom, I know what I’m going to share at circle time. Biff! And I’m going to talk about my spina bifida.”

“What an excellent idea!” said Mom,  
“That’s very brave of you Eddie.”

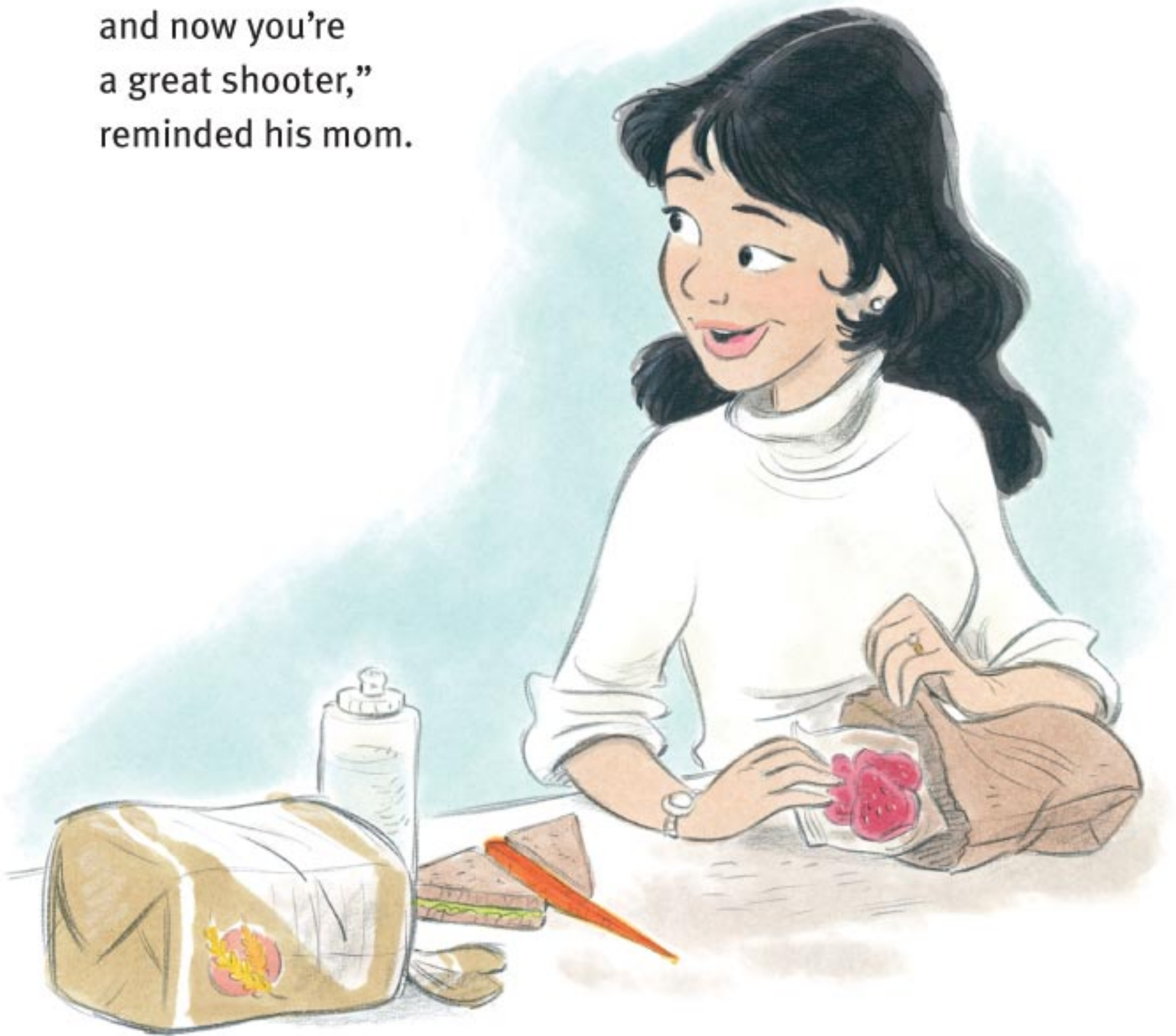


But on Monday morning Eddie didn't feel so brave.  
"I'm scared Mom," he said.

"What if the other kids laugh at me?  
What if they don't want to be my friend?"



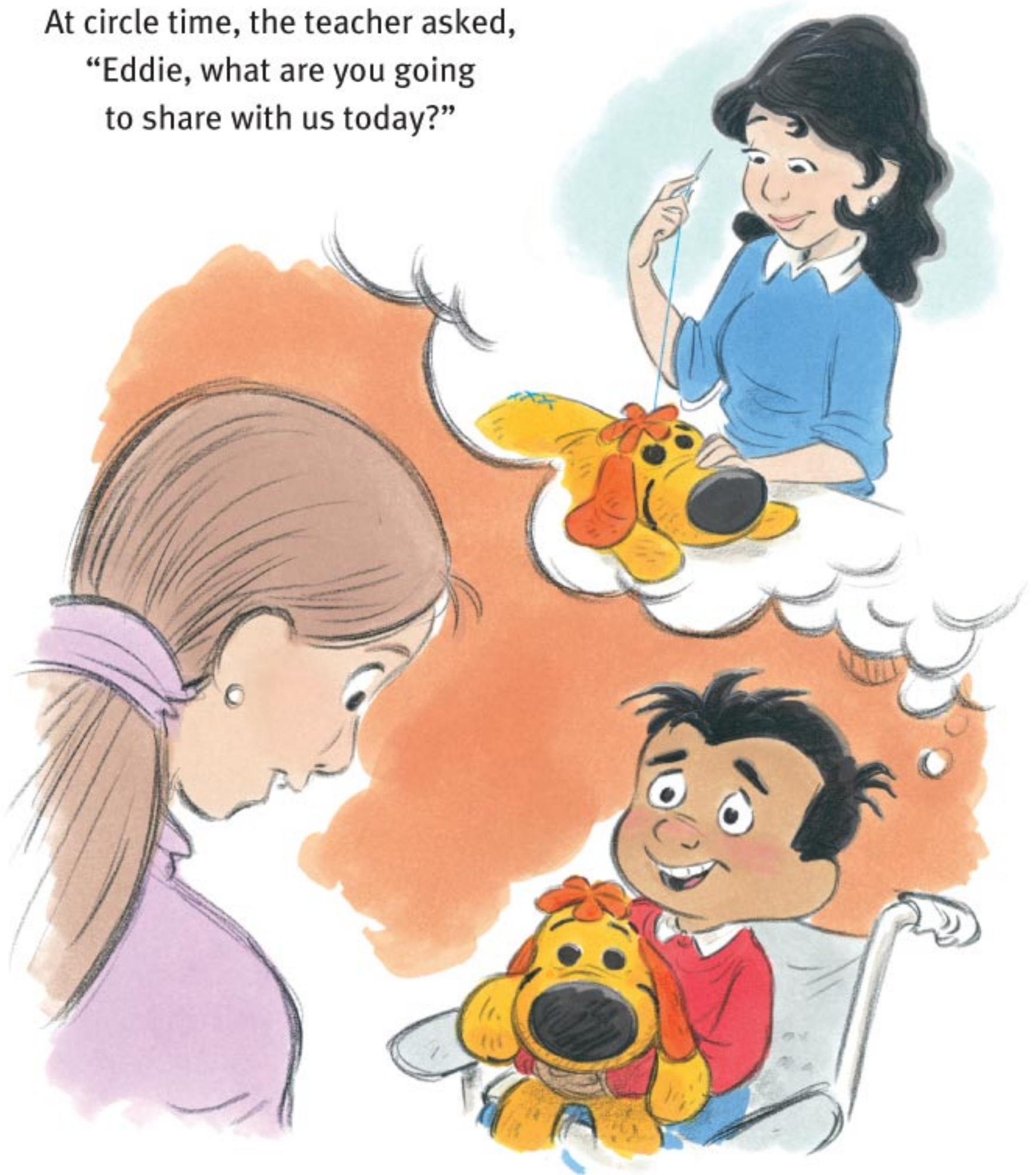
“You were scared to play basketball, but you practiced hard, and now you’re a great shooter,” reminded his mom.



“And you thought your friends would laugh at you for wanting to be a violinist, but now everyone enjoys listening to you play. I think you might be surprised what happens. And remember, I’ll be there if you need me.”



At circle time, the teacher asked,  
“Eddie, what are you going  
to share with us today?”



“My friend Biff.  
He’s special because my mom made him look just like me.”



Eddie took a deep breath and began to explain.  
“I was born with spina bifida.  
When I was a baby, I had an operation on my back.  
It made a scar.”



Eddie looked around for his mom. She smiled her big smile.  
“Biff has a scar, just like me. See?”  
“Wow!” said all the children together.



“I had another operation, here on my head,”  
said Eddie more boldly.  
He bent forward to show his scar.



“It's where the doctor put in a shunt.”  
Everyone wanted to get a better look.



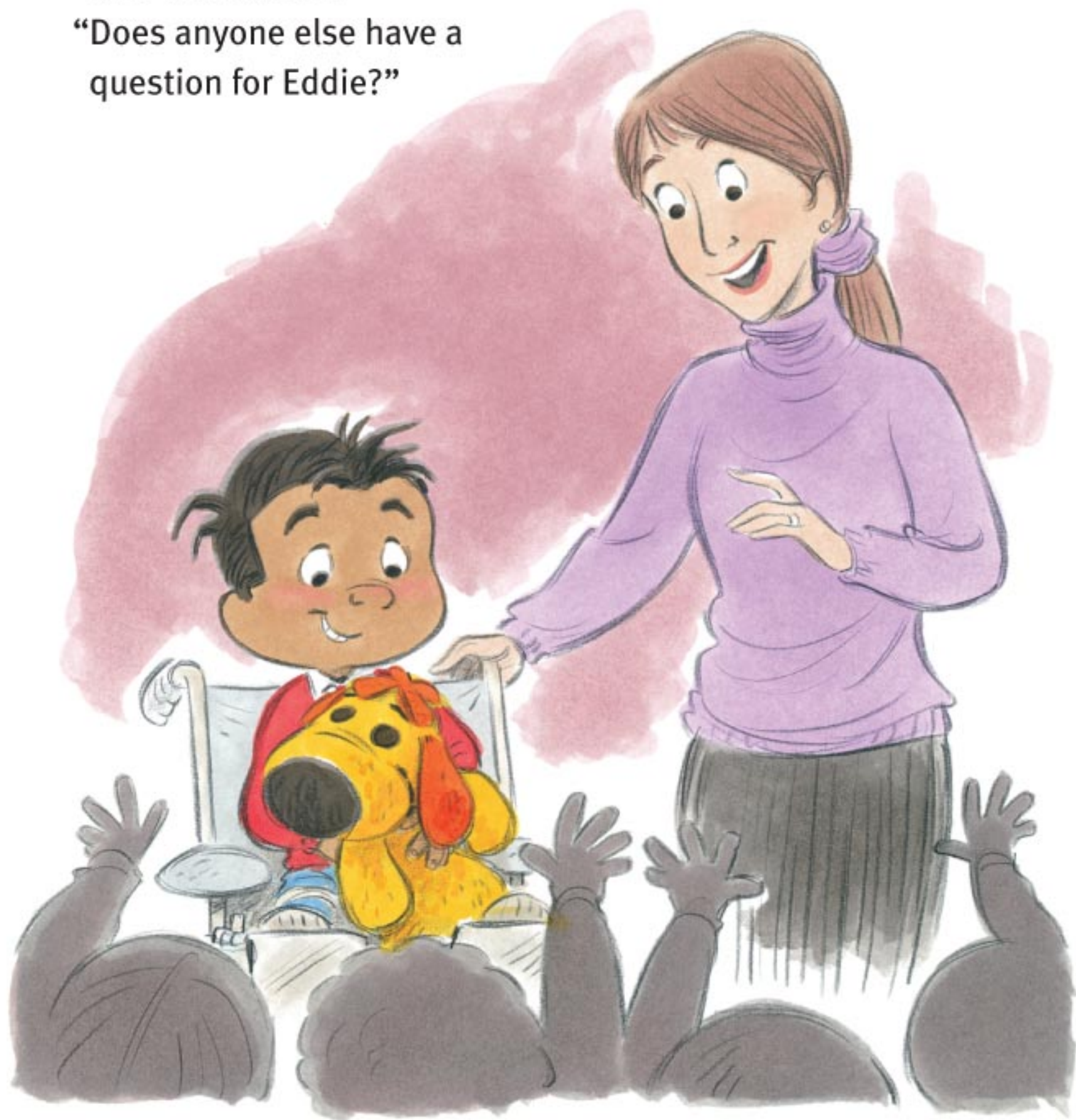
“What’s a shunt?” asked a girl in the front row.  
“It’s a little tube. It takes fluid away from my brain,”  
Eddie answered proudly.



“Biff has a shunt scar, just like me!”

“This is very interesting, Eddie,”  
said the teacher.

“Does anyone else have a  
question for Eddie?”



Lots of hands went up.  
It seemed that everyone had a question.  
Eddie felt *very* important.



“Why do you wear braces?”  
asked the boy in the red shirt.

“They support my legs,  
so I don’t feel wobbly,”  
explained Eddie.



“Look, Biff has wobbly legs and  
small feet, just like me!”



“Can you catch spina bifida?”  
asked another little girl.  
“No, you have to be born with it,”  
replied Eddie.



“Can I touch your scar?”  
“Can I feel your legs?”  
“Can I try on your braces?”  
asked the children all at once.



The teacher rang her little bell.

“Settle down, children. Everyone will  
have a chance to talk to Eddie at recess . . .  
if that’s okay with Eddie?”



It was okay with Eddie.  
He liked sharing with his friends.



“Well done, Eddie!” said the teacher at recess.  
“You found something really special  
to share today.”



“Yes!” agreed Eddie as he did a wheelie in his chair.  
“Biff and MEEEEEEEEEE!”







## TIPS PAGES

The tips pages, together with the following activity pages, offer simple answers to questions your young child may ask, as well as, activity suggestions. Both can help your child to better understand spina bifida and explore new ways to enrich his life.

Used together, the tips and activity pages will help you open and guide discussion about the following issues, which are important for your child's health and sense of self:

- Movement • Bathroom Routines • Exercises • Physical Activity • Diet • Scars

As you talk to your child about spina bifida, remember:

- It's okay to say, "I don't know" to a question from your child. Reassure her that her question is important and you will get help to find the answer.
- It's okay if you can't find the words to use. You'll have more than one chance to talk about these things.
- It's okay if your child asks the same question several times. Most children need to do this before they understand a complex condition like spina bifida.
- It's okay, and encouraged, to seek support for yourself and your family from other caregivers, doctors, therapists and local support groups.

Typical questions, complaints and concerns your young child may raise, and suggested replies are provided throughout this section.

### What is spina bifida?

*"Spina bifida is a medical condition you were born with. When you were in mommy's tummy, part of your back formed differently than other children's. This can make it hard for your body to move and go to the bathroom. So you may pee, poop and move differently than other children."*

*"Nothing that you, Mommy or Daddy did caused your spina bifida. No one knows exactly how it is caused."*

### Will I always be like this?

*"Yes, you will have spina bifida all your life. This means you may have to use braces and crutches or a wheelchair to move around. You will also always have to pay attention to how you use the bathroom. But as you get older you may not have to wear diapers."*

### Will people love me?

*"That's a great question and easy to answer. Yes! They already do!"*



## Movement

Young children have a strong natural curiosity about visible differences. Your child may ask why his movement, legs and feet may be different than other children. After providing answers, explore how the way your child moves can have hidden gifts.

### Why can't I walk like other children?

*"Your back formed differently than other children's, so you may not feel your legs and feet the way they do. This can make it difficult for you to walk. You may use a wheelchair, walker, crutches or braces to move around."*

### Why do I move differently than other children with spina bifida?

*"Just as children can have different color eyes, they can have different kinds of spina bifida. There are many types of spina bifida. The kind you have determines how you move and what equipment you use to get to where you want to go."*



### Why are my legs and feet small?

*"Legs and feet need to move a lot to grow. Because you only move a little on yours, they stay small."*



### Suggested Activities to Help Your Child:

- Use activity page A and invite your child to find the equipment that she uses to move around.
- Remind your child how Eddie used a wheelchair and walker to get around and how he had fun with them. He made a tent of sheets, cleared the table faster than his sister and did wheelies. Ask your child for ideas on how to have fun with his wheelchair, walker, crutches or braces.
- Help your child list what she enjoys about her equipment. For example, she might like helping others carry their backpacks, or being able to decorate her walker or crutches with stickers.





## Bathroom Routines

Your child may be self-conscious that he uses the bathroom differently than other children do. To help address this concern, explain why particular supplies and routines are needed and, together, develop playful ways of coping.

### Why do I use the bathroom differently?



*“Because your body formed differently, it can’t tell you when it’s time to pee or poop. So you use other ways to go to the bathroom. You wear diapers and catheterize. This is how you help your body to avoid ‘bathroom accidents.’”*

### I don't want to wear diapers. My friends don't. It's not fair.



*“It sounds like you are feeling mad and sad. That’s okay. I’m glad you told me. Your friends don’t wear diapers because their bodies can tell them when to pee and poop. You may be able to wear only underwear, just like they do, when you are older. Would you like to start wearing underwear over your diapers right now?”*

### I want to run away and hide when I have to ask for help to go to the bathroom.

*“I’m glad you told me how you’re feeling. Let’s try and solve this problem together. There are different ways you can let grown-ups know it’s time for you to go to the bathroom. You can say, ‘I need help,’ use a secret code or make a hand signal, like holding up one finger up in the air.”*

### Suggested Activities to Help Your Child:



- Use activity page B and invite your child to find the supplies she uses to go to the bathroom.



- Encourage your child to participate in his cathing and diaper changing, as appropriate. Good ways to start this involvement are to encourage hand washing and the gathering and replacement of needed bathroom supplies.
- Ask what secret code your child would like to use as a way of asking for help in going to the bathroom. She might choose the name of a favorite cartoon character or movie hero and when she needs help to go to the bathroom simply say, for example, “Yoda.”





## Exercises

Your child will need support to do his stretches and wheelchair push-ups regularly. To help establish a routine, explain why the exercises are important and make them fun.

### Why do I have to do my exercises?

*“Your long sit stretch and leg exercises can make it easier for you to move, and your wheelchair push-ups will help protect your skin from sores when you sit too much. Exercising is very important!”*

### I don't want to do my exercises!

*“I know it's hard, but exercises need to be done every day. Let's make this a special time! You can color, do a jigsaw puzzle or play a game. What favorite things would you like to do while you exercise?”*



### Suggested Activities to Help Your Child:

- Use activity page C and invite your child to mark each day she exercises on the monthly calendars. You can make or purchase a simple calendar for your child to use for subsequent months.



- Create a “together time” ritual around exercising. A good goal for the leg stretch is 1-2 minutes, before breakfast and dinner. The long sit stretch should be done daily, for 5-10 minutes. These are great opportunities for a regular loving ritual. You could sing or read together and end each exercise with a special hug.
- Make exercising fun! A good goal for wheelchair push-ups is 10 seconds, every hour. A stopwatch set to beep on the hour, will help your child establish a routine.
- He could also sing the “Happy Birthday” song, which lasts 10 seconds. For a fun twist, suggest that he use the word “me” instead of a name at the end of each line. Then each line in the song will sound like the last line in the book, when Eddie says, “Biff and Meeeeeee!”





## Physical Activity

All children need physical activity. Encourage your child by explaining how this makes her body stronger, going to the bathroom easier and offers new ways to play with friends. Then, ask your child to choose which of the following options he would like to try first.



### Suggested Activities to Help Your Child:

#### INDOOR

- Use activity page D and invite your child to draw herself playing her favorite sport.
- Using magnetic letters to form words high up on your refrigerator door
- “Drawing” on the bathroom mirror with shaving cream
- Blowing bubbles in the air for your child to pop
- Creating treasure hunts around your home
- Finger painting, or coloring, on paper taped to the wall

#### OUTDOOR

- Taking a neighbor’s dog for a walk (supervised by an adult)
- Flying a kite
- Watering the garden
- Playing Tag
- Creating an obstacle course



A suggested obstacle course for your child and his friends could include weaving between three empty one-gallon milk containers, going under a towel hung between a window sill and a chair, and tossing a frisbee into a cardboard box.



As you select activities, games and toys it is important that your child only plays with, and uses, products that are latex free. Allergic reactions to latex may include cold-like symptoms (i.e. watery eyes, sneezing and coughing); rashes, sores and hives; and breathing problems.

Your medical support team can guide you to substitute products and/or where to obtain such a list.



## Diet

Healthy eating is important for all children. Your child will also need to learn what foods and drinks help prevent constipation. To help your child make better decisions when choosing food and drink, explain why these are important, acknowledge her cooperation and have fun with food presentation.

### Why do I have to eat so many fruits and vegetables?

*“Eating fruits and vegetables and drinking lots of water helps your body to poop. Without these you get constipated. Being constipated is when your poop is hard to push out.”*

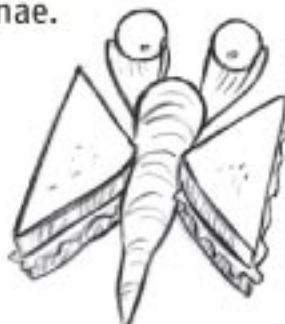
### Suggested Activities to Help Your Child:

- Use activity page E and invite your child to find the foods and drinks that prevent constipation.
- Encourage your child to drink 4 cups of water a day and take a water bottle everywhere, just like Eddie does. Remind him that drinking water helps manage constipation better than sports drinks, sweet drinks and sodas.
- Try the following food sculptures, or make up some of your own!

To make a **robot**, cut a pear in half, from top to bottom. Use raisins for the feet and nose, whole wheat Cheerios for the eyes and mouth and dates for the arms.



To create a **butterfly**, cut a low-fat cheese or chicken salad sandwich into two triangles. Add a carrot for a body and celery sticks and tomatoes for the antennae.



To make a **spider**, spread low-fat peanut butter on a whole wheat cracker for the body, add eight pretzel sticks for the legs and two raisins for the eyes.



## Scars

Children don't like to be different. When a child has a scar and it's noticeable, it may attract unwanted attention and comment. Support your child by helping her to recognize and express her feelings about having scars.

### Suggested Activities to Help Your Child:

- Use activity page F and invite your child to identify where he has scars.
- Read aloud, from activity page F: *"Scars are medals made of skin that show you have been very brave."* Ask your child how she feels about her scars. Remember you do not always need to respond or discuss. You can simply listen and then repeat, in your own words, what your child has just said. This will encourage your child to continue to talk freely and openly.
- Ask your child to think of other people who might also have scars. Realizing that professional athletes and police officers may have scars from accidents or operations may help him understand that it is quite common to have a scar.
- Sew "scars" onto your child's favorite stuffed toy, as Eddie's mom did with Biff. It can help provide comfort, self-acceptance and discussion about looking different and having scars.





## ACTIVITY PAGES

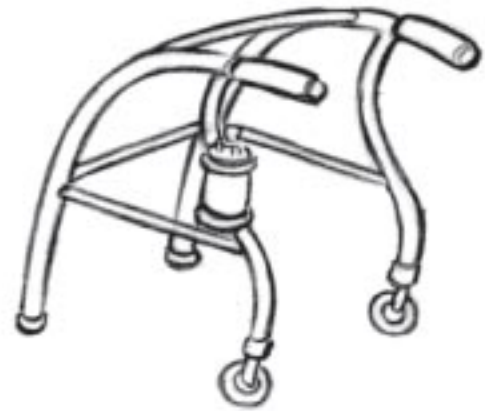
The following pages address issues of importance to young children with spina bifida. Challenges your child may face include his movement, bathroom routines, need for exercises and physical activity, diet and scars. Completing these pages will help her recognize aspects of her own life with spina bifida.

Each page is perforated so it can be easily detached, colored and displayed. Your child will be most successful if he colors with fine-line markers.

As, or after, your child completes or colors an activity page you can use related material in the tips pages. This affords a natural opportunity to initiate discussion about what could be a sensitive issue to your child. Combined use of the tips and activity pages will help you and your child better understand spina bifida and explore new possibilities for his life.



Put a circle around the equipment you use to move around.



Artist: \_\_\_\_\_



Find the 7 supplies you use when going to the bathroom.



catheter



soap



lubriwipes



kidney basin



towel



diaper



lubricant



Artist:

Put a mark on the calendars each day you exercise like Eddie.



leg stretch

MONTH \_\_\_\_\_


MONTH \_\_\_\_\_




wheelchair  
push-ups



long sit stretch

MONTH \_\_\_\_\_


Artist:

\_\_\_\_\_





Draw a picture of yourself playing your favorite sport.

Artist:



Color in all the foods that help you poop.



Artist:

\_\_\_\_\_





Put an "x" on the place(s) where you have a scar.



Scars are medals made of skin that show you have been very brave.

Artist: \_\_\_\_\_



If you need another copy please download it from [www.myspinabifidabook.org](http://www.myspinabifidabook.org), where your child can also enjoy an audio version of the story and an interactive version of the book.

This book was made available by generous funding from First 5 LA.



*Champions For Our Children*

First 5 LA is a unique child-advocacy organization created by California voters to invest tobacco tax revenues in programs for improving the lives of children in Los Angeles County, from prenatal through age 5.

First 5 LA champions health, education and safety causes concerning young children and families.