



LET'S MAKE A
Memory

★ THE
INSPIRED
★ BY ★
SERIES

A neuromyelitis optica spectrum
disorder (NMOSD) journey



Let's Make a Memory
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This book is inspired by Arlin and Bella, a real mother and daughter impacted by Neuromyelitis Optica Spectrum Disorder. We want to thank Arlin and Bella for bringing this story to life.

“We feel honored to share our story. With this book, we hope to show others that even though living with a rare disease may come with challenges, it’s not a barrier to making many wonderful memories.”

Arlin & Bella



“I know, but it’s so hard to go to sleep!” Zoe says, sitting up to hug her knees.

“Excited or nervous?” Kim asks.

“Both!” Zoe says quietly. “Have you ever felt like that?”

“Oh, yes,” Kim says as she sits on the edge of Zoe’s bed. “Many times. Sometimes fun things can be a little scary, too.” She laughs. “I’ve always thought there should be a word for that.”

After a pause, Zoe says, “You mean like...‘nerxcited’?”

In a moonlit room in a cozy yellow house, there’s an excited girl getting ready for bed.

Zoe knows it’s time for sleep, but the moon is shining like a spotlight on her new blue dress hanging on the closet door. The sparkles on the dress shimmer in the light, and she thinks, *I’m going to sparkle tomorrow, too*. She closes her eyes and pictures herself at her first school dance, and she can’t help the grin that spreads across her face.

“Hey, honey, it’s time for bed,” Zoe’s mom says, leaning in from the doorway. Even in the dark, Kim can see Zoe’s excitement, and she smiles. “You don’t want to be tired for the big dance.”



They both laugh. “‘Nerxcited’ is the perfect word! It’s natural to feel ‘nerxcited’ about new things,” Kim says. “Remember how you felt just before getting on the roller coaster at Adventure Land?”

“Oh my gosh, that was definitely ‘nerxciting!’” Zoe’s eyes widen, thinking back. “Remember how we had to wait in that super long line, though?”

Kim tilts her head and smiles. “I know it sounds funny to you, but I actually liked waiting in that line.”

“Oh my gosh, Mom, no one likes long lines!”

“I try not to show it, but it can be hard to keep up with you sometimes,” Kim says. “It’s a lot for me to walk around an amusement park. So, waiting in line like that made it easier to catch my breath and soak up your excitement.”





Zoe looks over at the stuffed turtle on her dresser. “I still have Shelly from playing the ring toss—you saw me win!”

“Yep, and I got to watch you scream your head off on the Twirly Whirly!” Kim laughs. “I couldn’t ride it with you, but seeing you have fun is good enough for me.”

Zoe’s forehead wrinkles. “Don’t you want to have fun, too?”

“Seeing that classic Zoe smile is fun for me!” Kim says, tipping Zoe’s chin up with her thumb. “Just like that time we saw your first Broadway musical. Your face lit up like Times Square!”

Zoe looks down, realizes she's wearing the T-shirt from the show, and remembers how she slept in it for a whole month after the trip.

"I loved that trip; it was perfect. It was so cool to finally see New York City and be in a real taxi! My friends still get jealous when I talk about it," Zoe says, remembering when they saw the sign for the show through the taxi window. Her mom had grabbed her hand, the lights dancing in their eyes with a glittery thrill.

"That was cool," Kim says. "But I'm just happy we were able to get a taxi to take us right to the door. The city is so fun, but there's a lot of walking and a ton of people. When there are that many people, sometimes I get a little turned around because it's hard to see and move through them all. That's why we sat so close at the show. It was nice for me not to have to go up all those stairs."



"So, that's why we had such good seats..." Trailing off, Zoe thinks back on their trip to New York City and how hard her mom had worked to make sure they could do all the things Zoe wanted to. When Zoe wanted to walk through Central Park, her mom suggested they ride in a carriage. And knowing it was Zoe's dream to ride to the top of the Empire State Building, her mom had called ahead for a special elevator pass so she could avoid the extra stairs.

"Mom, I didn't know how hard all of those things were for you," Zoe says.

“Well, I didn’t want you to worry,” Kim says. “I wanted you to have the trip of a lifetime.” Taking Zoe’s hand, she adds, “Things are a little different for me sometimes. As you know, I have to walk slow, and sometimes my condition makes it hard to see things well.”

“Yeah, I know.” Zoe bites her lip. “I don’t think I really ever understood why, though.”

“You see, my body is different than yours,” Kim says. “You know how when you’re sick, your body fights hard to get better? Well, sometimes, my body gets a little confused.”

“What, like you get dizzy or something?”

“Sort of.” Kim laughs. “You know that I have a condition. I’ve explained to you in the past that I have to go slower sometimes and that I can’t always participate in every activity. But I think you’re old enough now to learn a little more about what’s going on with my body.



“My doctor diagnosed me with a condition called neuromyelitis optica spectrum disorder. It’s pretty rare.”

“Oof, that’s a mouthful,” Zoe says.

“Most people call it NMOSD for short...but,” Kim says and laughs, “I know that doesn’t really make it easier to say. It can mean different things for each person. For some people, their body feels more tired or weak, and sometimes there are even moments when it’s painful, which can make everyday life pretty tough. For me, it’s something that makes it hard to move or see or even feel things sometimes. Like, you know that time when you accidentally put your hand on the hot stove?”

Zoe groans at the memory. “Oh yeah, that hurt.”

“Of course, and the pain made you pull your hand away from the stove quick, too. But my body doesn’t always feel things as much as others.”

Zoe looks down at their hands clasped together. “Can you feel it when you hold my hand?”

“Yes, sometimes I can, but other times it’s just not as loud.”

“Loud?” Zoe asks.

“It’s the best way I can describe it. For you, you’re touching and feeling things all day, every day without even thinking about it. When you touched that hot stove, you felt the pain right away because your brain made it ‘loud’ so you wouldn’t miss it. It’s not always like that for me.”

“It sounds hard. What makes you still want to go out and go places?”

Kim pauses for a moment, thinking about how precious each of their memories is to her. “Because when we go places, we make memories, and those memories cheer me up on the days my NMOSD is making it hard to walk or see clearly.”

“So, what do things look like for you, then?” Zoe asks.

Leaning back, Kim knows it might be hard for Zoe to imagine what things look like through someone else’s eyes, and she thinks about how she can explain to Zoe what she sees every day.

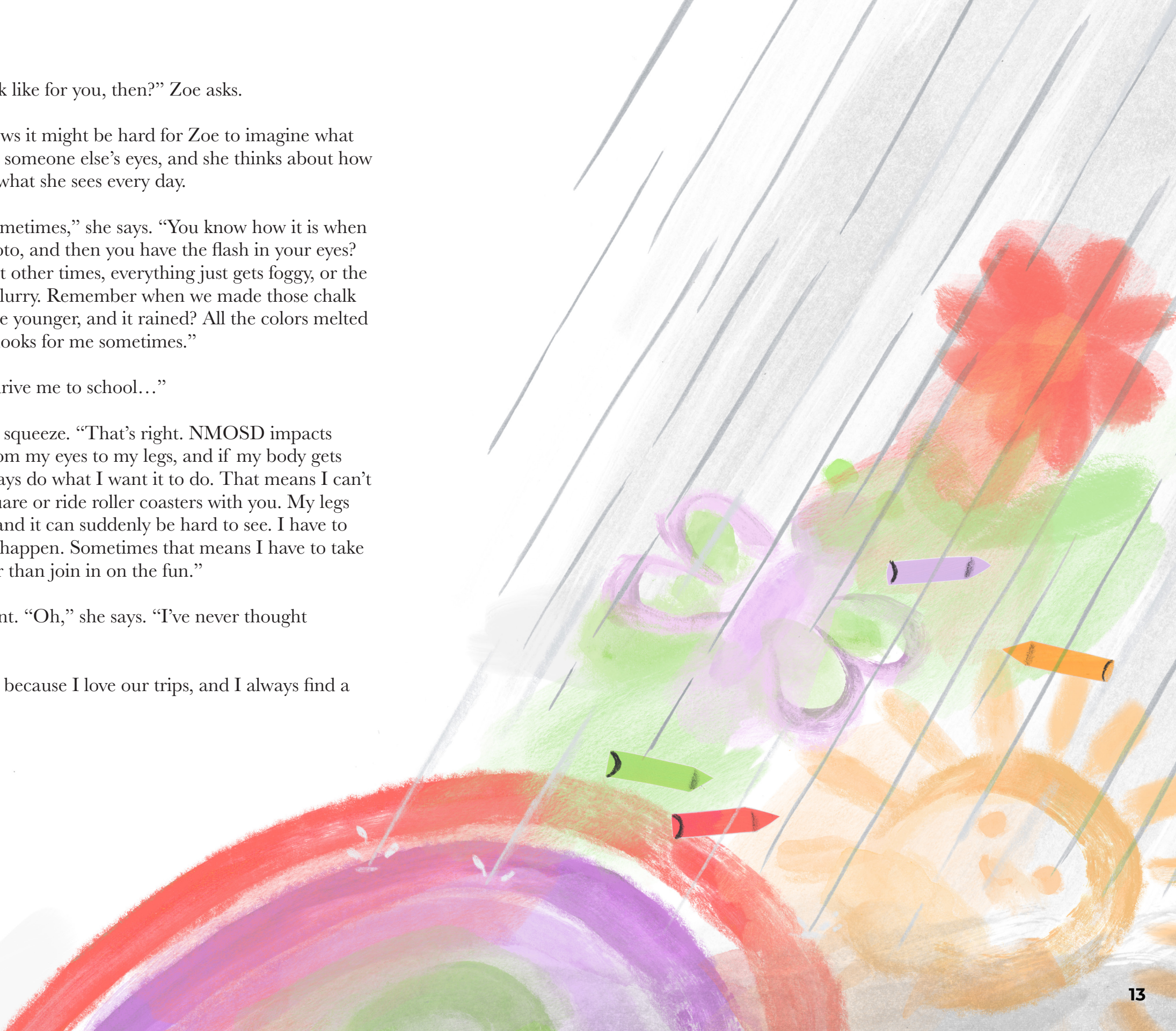
“It can look different sometimes,” she says. “You know how it is when someone takes your photo, and then you have the flash in your eyes? It’s kind of like that. But other times, everything just gets foggy, or the world around me gets blurry. Remember when we made those chalk drawings when you were younger, and it rained? All the colors melted together. That’s how it looks for me sometimes.”

“That’s why you can’t drive me to school...”

Kim gives Zoe’s hand a squeeze. “That’s right. NMOSD impacts me in different ways, from my eyes to my legs, and if my body gets confused, it doesn’t always do what I want it to do. That means I can’t walk around Times Square or ride roller coasters with you. My legs might get really heavy, and it can suddenly be hard to see. I have to plan for those things to happen. Sometimes that means I have to take it slow and watch rather than join in on the fun.”

Zoe pauses for a moment. “Oh,” she says. “I’ve never thought about that...”

“I know, but that’s okay because I love our trips, and I always find a way to have fun.”





“Don’t laugh too hard!” Kim jokes. “I do know how to ski. I used to go with my family when I was your age; that’s why I wanted you to experience it, too.”

“Oh, I just thought you didn’t know how.”

Kim sighs. “Well, these days, skiing and my body don’t go well together. But I loved sipping on my hot chocolate in the lodge and knowing how much fun you were having. Some of the simpler memories are my favorite,” Kim says. “Like listening to you sing show tunes for hours on end. Or when we have our baking bonanzas. Sometimes it’s hard for me to read the recipes, but you’re so good about checking them for me. Plus, I love being your personal taster!”

Kim and Zoe giggle.

“So, which trip was your favorite?”

“You’re not going to believe it, but I loved when we went skiing!” Kim laughs.

“But Mom, you didn’t even ski! You put on your ski gear, but you stayed in the lodge.”

“True, but that doesn’t mean I wasn’t a part of the adventure,” Kim says. “Can you picture me on skis?”

Zoe tries to hide her giggles.

“Alright, I think it’s time for bed,” Kim says. “You better get some sleep before your big night of dancing tomorrow!”

Kim gives Zoe a kiss on the head and turns off the light. Zoe lays her head down on her pillow and thinks back on what her mom has said.

She pictures her mom on the bench waving and watching her ride the roller coaster. She remembers her walking slowly down the steps at the theater. Zoe loved riding the Twirly Whirly and seeing the big Broadway stage, but she hadn’t thought about how her mom’s memories might be different.

As Zoe’s eyes flutter closed, she takes one last look at her moonlit dress and wonders how her mom’s memories of tomorrow might be different, too.

The next day, Zoe shimmers with energy as she gets ready for the dance. Amused, Kim watches from the couch as Zoe sings and twirls around the room, dancing with her dress on the hanger.

Kim laughs. “So, I take it you aren’t feeling ‘nerxcited’ anymore?”

“Nope. Now I’m just plain excited! I honestly can’t wait for the dance and taking pictures with my friends!”

“Where are they doing pictures again?”

“On the steps in front of the school. It’s all decorated for the dance. There’s a million balloons!” Zoe says giddily. “You’re coming, right?”

“Of course, but let’s see you in that dress first!”

Zoe glides out in her gown, waving to an invisible crowd. Kim claps and cheers. “You look beautiful! But just one more thing.” Kim tucks a small blue flower into Zoe’s hair. “Perfect. I wore a flower for my first dance, too.”

“I’ve never seen you dance. Do you ever miss doing stuff like that?”

“Well, I always loved dancing, and if I do say so myself, I was pretty good at it. But I don’t know if you would want to see that!” Kim laughs. “It’s just hard for me now if I’m in a crowded or dark place, so I don’t get to go out dancing very often.”

“Why didn’t you ever tell me more about all this NM...ABC stuff when I was younger?” Zoe asks.





“It’s NMOSD.” Kim laughs and then pauses. “I guess the best answer is that I should’ve talked to you about it. I know it seems like I know a lot, but when you were little, I was still learning how to be a parent. Moms always want to seem like superheroes to our kids. But at the end of the day, we’re just people, too.”

Zoe tries to picture her mom before she was her mom. She thinks about Kim riding roller coasters and dancing and going on ski trips with her family. She thinks about her mom before she had to worry about NMOSD.

When Kim couldn’t ride roller coasters or go skiing with her, Zoe thought it was just because her mom was being boring. She realizes now that it wasn’t because her mom didn’t want to do those things, but because she couldn’t.



“I feel bad,” Zoe whispers. “I wish I would’ve asked before what it was like for you.”

Kim pushes a strand of hair behind Zoe’s ear and smiles softly. “It’s okay, Zoe-bear. It’s good that we’re talking about it now.”

Zoe hugs Kim. “Don’t worry, Mom. I’ll dance for both of us tonight.”

“We’d better get going,” Kim says, looking at the clock. “I’ll call us a car!”



Zoe notices that she’s never seen her mom behind the wheel of a car; they’ve always had to call a friend or a driver to take them places. Most of the time, she didn’t think twice about it, but now she understands that this is just another way her mom has to do things a little differently.

At the school, Kim watches as Zoe and her friends pose for the camera on the front steps. Kim can't help but smile as she sees Zoe shine with her friends.

One of the other parents calls out, "Let's get a photo with the moms and their girls!"

As the other moms start to climb the stairs, Zoe remembers that her mom can't climb so many stairs by herself.

"It's a little steep for me," Kim says from the bottom of the stairs. "Just go ahead!"

Zoe looks at her mom and wonders how many times she has been left waiting at the bottom of the stairs. She thinks again about all their memories and how her mom has always done whatever it took to make sure it was fun for her. Looking back, Zoe realizes that the best part was just having her mom beside her.

Kim hears the *click-click* of Zoe's shoes as she runs down the steps to join her.

"Alright, Mom; we've got this," Zoe says, taking her arm. As they slowly climb the stairs, she whispers, "This is my new favorite memory."



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