

Excerpts from *Out of My Mind*

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Chapter 1

1 Words.

I'm surrounded by thousands of words. Maybe millions.

Cathedral. Mayonnaise. Pomegranate.

Mississippi. Neapolitan. Hippopotamus.

Silky. Terrifying. Iridescent.

Tickle. Sneeze. Wish. Worry.

Words have always swirled around me like snowflakes—each one delicate and different, each one melting untouched in my hands.

2 Deep within me, words pile up in huge drifts. Mountains of phrases and sentences and connected ideas. Clever expressions. Jokes. Love songs.

From the time I was really little—maybe just a few months old—words were like sweet, liquid gifts, and I drank them like lemonade. I could almost taste them. They made my jumbled thoughts and feelings have substance. My parents have always blanketed me with conversation. They chattered and babbled. They verbalized and vocalized. My father sang to me. My mother whispered her strength into my ear.

Every word my parents spoke to me or about me I absorbed and kept and remembered. All of them.

I have no idea how I untangled the complicated process of words and thought, but it happened quickly and naturally. By the time I was two, all my memories had words, and all my words had meanings.

But only in my head.

I have never spoken one single word. I am almost eleven years old.

Chapter 2

3 I can't talk. I can't walk. I can't feed myself or take myself to the bathroom. Big bummer.

My arms and hands are pretty stiff, but I can mash the buttons on the TV remote and move my wheelchair with the help of knobs that I can grab on the wheels. I can't hold a spoon or a pencil without dropping it. And my balance is like zip—Humpty Dumpty had more control than I do.

When people look at me, I guess they see a girl with short, dark, curly hair strapped into a pink wheelchair. By the way, there is nothing cute about a pink wheelchair. Pink doesn't change a thing.

4 They'd see a girl with dark brown eyes that are full of curiosity. But one of them is slightly out of whack.

Her head wobbles a little.

Sometimes she drools.

She's really tiny for a girl who is age ten and three quarters.

Her legs are very thin, probably because they've never been used.

Her body tends to move on its own agenda, with feet sometimes kicking out unexpectedly and arms occasionally flailing, connecting with whatever is close by—a stack of CDs, a bowl of soup, a vase of roses.

Not a whole lot of control there.

After folks got finished making a list of my problems, they might take time to notice that I have a fairly nice smile and deep dimples—I think my dimples are cool.

I wear tiny gold earrings.

Sometimes people never even ask my name, like it's not important or something. It is. My name is Melody.

I can remember way back to when I was really, really young. Of course, it's hard to separate real memories from the videos of me that Dad took on his camcorder. I've watched those things a million times.

5 Mom bringing me home from the hospital—her face showing smiles, but her eyes squinted with worry.

Melody tucked into a tiny baby bathtub. My arms and legs looked so skinny. I didn't splash or kick.

Melody propped with blankets on the living room sofa—a look of contentment on my face. I never cried much when I was a baby; Mom swears it's true.

Mom massaging me with lotion after a bath—I can still smell the lavender—then wrapping me in a fluffy towel with a little hood built into one corner.

Dad took videos of me getting fed, getting changed, and even me sleeping. As I got older, I guess he was waiting for me to turn over, and sit up, and walk. I never did.

But I did absorb everything. I began to recognize noises and smells and tastes. The *whump* and *whoosh* of the furnace coming alive each morning. The tangy odor of heated dust as the house warmed up. The feel of a sneeze in the back of my throat.

And music. Songs floated through me and stayed. Lullabies, mixed with the soft smells of bedtime, slept with me. Harmonies made me smile. It's like I've always had a painted musical sound track playing background to my life. I can almost hear colors and smell images when music is played.

6 Mom loves classical. Big, booming Beethoven symphonies blast from her CD player all day long. Those pieces always seem to be bright blue as I listen, and they smell like fresh paint.

Dad is partial to jazz, and every chance he gets, he winks at me, takes out Mom's Mozart disc, then pops in a CD of Miles Davis or Woody Herman. Jazz to me sounds brown and tan, and it smells like wet dirt. Jazz music drives Mom crazy, which is probably why Dad puts it on.

"Jazz makes me itch," she says with a frown as Dad's music explodes into the kitchen.

Dad goes to her, gently scratches her arms and back, then engulfs her in a hug. She stops frowning. But she changes it back to classical again as soon as Dad leaves the room.

For some reason, I've always loved country music—loud, guitar-strumming, broken-heart music. Country is lemons—not sour, but sugar sweet and tangy. Lemon cake icing, cool, fresh lemonade! Lemon, lemon, lemon! Love it.

When I was really little, I remember sitting in our kitchen, being fed breakfast by Mom, and a song came on the radio that made me screech with joy.

So I'm singin'

Elvira, Elvira

My heart's on fire, Elvira

7 *Giddy up oom poppa oom poppa mow mow*

Giddy up oom poppa oom poppa mow mow

Heigh-ho Silver, away

How did I already know the words and rhythms to that song? I have no idea. It must have seeped into my memory somehow—maybe from a radio or TV program. Anyway, I almost fell out of my chair. I scrunched up my face and jerked and twitched as I tried to point to the radio. I wanted to hear the song again. But Mom just looked at me like I was nuts.

How could she understand that I loved the song "Elvira" by the Oak Ridge Boys when I barely understood it myself? I had no way to explain how I could smell freshly sliced lemons and see citrus-toned musical notes in my mind as it played.

If I had a paintbrush . . . wow! What a painting that would be!

But Mom just shook her head and kept on spooning applesauce into my mouth. There's so much my mother doesn't know.

I suppose it's a good thing to be unable to forget anything—being able to keep every instant of my life crammed inside my head. But it's also very frustrating. I can't share any of it, and none of it ever goes away.

8 I remember stupid stuff, like the feel of a lump of oatmeal stuck on the roof of my mouth or the taste of toothpaste not rinsed off my teeth.

The smell of early-morning coffee is a permanent memory, mixed up with the smell of bacon and the background yakking of the morning news people.

Mostly, though, I remember words. Very early I figured out there were millions of words in the world. Everyone around me was able to bring them out with no effort.

The salespeople on television: *Buy one and get two free! For a limited time only.*

The mailman who came to the door: *Mornin', Mrs. Brooks. How's the baby?*

The choir at church: *Hallelujah, hallelujah, amen.*

The checkout clerk at the grocery store: *Thanks for shopping with us today.*

Everybody uses words to express themselves. Except me. And I bet most people don't realize the real power of words. But I do.

Thoughts need words. Words need a voice.

I love the smell of my mother's hair after she washes it.

I love the feel of the scratchy stubble on my father's face before he shaves.

But I've never been able to tell them.

Chapter 3

- 9 I guess I figured out I was different a little at a time. Since I never had trouble thinking or remembering, it actually sort of surprised me that I couldn't do stuff. And it made me angry.

My father brought home a small stuffed cat for me when I was really little—less than a year old, I'm sure. It was white and soft and just the right size for chubby baby fingers to pick up. I was sitting in one of those baby carriers on the floor—strapped in and safe as I checked out my world of green shag carpet and matching sofa. Mom placed the toy cat in my hands, and I smiled.

- 10 "Here, Melody. Daddy brought you a play-pretty," she cooed in that high-pitched voice that adults use with children.

Now, what's a "play-pretty"? As if it's not hard enough figuring out real stuff, I have to figure out the meanings of made-up words!

But I loved the soft coolness of the little cat's fur. Then it fell on the floor. Dad placed it in my hands the second time. I really wanted to hold it and hug it. But it fell on the floor once more. I remember I got mad and started to cry.

"Try again, sweetie," Dad said, sadness decorating the edges of his words. "You can do it." My parents placed the cat in my hands again and again. But every single time my little fingers could not hold it, and it tumbled back down to the carpet.

I did my own share of tumbling onto that rug. I guess that's why I remember it so well. It was green and ugly when you looked at it up close. I think shag carpeting was outdated even before I was born. I had lots of chances to figure out how the threads of a rug are woven as I lay there waiting for someone to pick me up. I couldn't roll over, so it was just an irritated me, the shag rug, and the smell of spilled sour soy milk in my face until I got rescued.

- 11 My parents would prop me up on the floor with pillows on either side of me when I wasn't in the baby seat. But I'd see a sunbeam coming through the window, turn my head to watch the little dust things that floated in it, and *bam*, I'd be face-first on the floor. I'd shriek, one of them would pick me up, quiet me, and try to balance me better within the cushions. Still I'd fall again in a few minutes.

But then Dad would do something funny, like try to jump like the frog we were watching on *Sesame Street*, and it would make me giggle. And I'd fall over again. I didn't *want* to fall or even mean to. I couldn't help it. I had no balance at all. None.

I didn't understand at the time, but my father did. He would sigh and pull me up onto his lap. He'd hug me close and hold up the little cat, or whatever toy I seemed to be interested in, so I could touch it.

Even though he sometimes made up his own vocabulary, Dad never spoke baby talk to me like my mother did. He always spoke to me as if he were talking to a grown-up, using real words and assuming I would understand him. He was right.

"Your life is not going to be easy, little Melody," he'd say quietly. "If I could switch places with you, I'd do it in a heartbeat. You know that, don't you?"

12 I just blinked, but I got what he meant. Sometimes his face would be wet with tears. He'd take me outside at night and whisper in my ear about the stars and the moon and the night wind.

"The stars up there are putting on a show just for you, kid," he'd say. "Look at that amazing display of sparkle! And feel that wind? It's trying to tickle your toes."

And during the day he would sometimes take off all the blankets that my mother insisted I be wrapped in and let me feel the warmth of the sun on my face and legs.

He had placed a bird feeder on our porch, and we would sit there together as the birds darted in, picking up seeds one at a time.

"That red one is a cardinal," he'd tell me, and "that one over there is a blue jay. They don't like each other much." And he'd chuckle.

What Dad did most was to sing to me. He has a clear voice that seems made for songs like "Yesterday" and "I Want to Hold Your Hand." Dad loves the Beatles. No, there's no figuring out parents and why they like stuff.

13 I've always had very good hearing. I remember listening to the sound of my father's car as he drove up our street, pulled into the driveway, and rustled in his pocket to find his house keys. He'd toss them on the bottom step, then I'd hear the sound of the refrigerator door open—twice. The first time he'd get something cold to drink. The second time he'd search for a huge hunk of Muenster cheese. Dad loves cheese. It doesn't agree with his digestive system very well, though. Dad also has the loudest, stinkiest farts in creation. I don't know how he manages to control them at work, or even if he does, but when he'd get home, he'd let them loose. They'd start as he walked up the stairs.

Step, fart.

Step, fart.

Step, fart.

I'd be laughing by the time he got to my room, and he'd lean over my bed and kiss me. His breath always smelled like peppermints.

When he could, Dad read to me. Even though I know he had to be tired, he'd smile, pick out a book or two, and I'd get to go to *Where the Wild Things Are*, or to where *The Cat in the Hat* was making a mess.

I probably knew the words by heart before he did. *Goodnight, Moon. Make Way for Ducklings*. Dozens more. The words to every single book my father ever read to me are forever tucked inside.

Here's the thing: I'm ridiculously smart, and I'm pretty sure I have a photographic memory. It's like I have a camera in my head, and if I see or hear something, I click it, and it stays.

14 I saw a special on PBS once on children who were geniuses. These kids could remember complicated strands of numbers and recall words and pictures in correct sequence and quote long passages of poetry. So can I.

I remember the toll-free number from every infomercial, and the mailing addresses and websites, too. If I ever need a new set of knives or the perfect exercise machine, I've got that information on file.

I know the names of the actors and actresses of all the shows, what time each program comes on, which channel, and which shows are repeats. I even remember the dialogue from each show and the commercials in between.

Sometimes I wish I had a delete button in my head.

I have a television remote control clicker attached to my wheelchair, very close to my right hand. On the left side I have a remote for the radio. I have enough control in my fist and thumbs to push the buttons so I can change the station, and I'm *really* glad of that! Twenty-four hours of big-time wrestling or the home shopping station can drive a person nuts! I can adjust the volume and even play DVDs if someone has popped one in the player for me. Lots of times I watch Dad's old videos of me.

15 But I also like the cable channels that talk about stuff like kings and the kingdoms they conquered or doctors and the diseases they cured. I've seen specials on volcanoes, shark attacks, dogs born with two heads, and the mummies of Egypt. I remember them all. Word for word.

Not that it does me a lot of good. Nobody knows it's there but me. Not even my mother, although she has this "Mom sense" that knows I understand stuff. But even that has its limits.

Nobody gets it. Nobody. Drives me crazy.

So every once in a while I *really* lose control. I mean really. My arms and legs get all tight and lash out like tree limbs in a storm. Even my face draws up. I sometimes can't breathe real well when this happens, but I have to because I need to screech and scream and jerk. They're not seizures. Those are medical and make you go to sleep.

These things—I call them my "tornado explosions"—are pieces of me. All the stuff that does not work gets balled up and hyped up. I can't stop, even though I want to, even though I know I'm freaking people out. I lose myself. It can get kinda ugly.

16 Once, when I was about four, Mom and I were in one of those superstores that sells everything from milk to sofas. I was still small enough to fit in the child seat in the front of the cart. Mom always came prepared and stuffed pillows on each side of me so I wouldn't tilt. Everything was fine. She tossed toilet paper and mouthwash and detergent into the cart, and I looked around, enjoying the ride.

Then, in the toy section, I saw them. Brightly colored packages of plastic blocks. Just that morning I had seen a warning on television about that toy—they were being recalled because the blocks had been painted with lead paint. Several children had already been hospitalized with lead poisoning, the report had said. But there they were—still on the shelf.

I pointed to them.

Mom said, "No, sweetie. You don't need those. You have enough toys."

I pointed again and screeched. I kicked my feet. "No!" Mom said more forcefully. "You are not going to have a tantrum on me!"

I didn't want the blocks. I wanted to tell her they were dangerous. I wanted her to tell somebody to get rid of them before a child got sick. But all I could do was scream and point and kick. So I did. I got louder.

Mom rushed out of the toy section, pushing the cart real fast. "Stop it!" she cried out at me.

I couldn't. It made me so angry that I couldn't tell her. The tornado took over. My arms became fighting sticks, my legs became weapons. I kicked at her with my feet. I screamed. I

17 kept pointing in the direction of those blocks.

People stared. Some pointed. Others looked away.

Mom got to the door of the store, yanked me out of the cart, and left it with all her selections sitting there. She was almost in tears when she got to the car. As she buckled me in my seat, she almost screamed at me, "What is *wrong* with you?"

Well, she knew the answer to that one, but she knew that was not my usual behavior. I gulped, sniffed, and finally calmed down. I hoped the people at the store watched the news.

When we got home, she called the doctor and told him about my crazy behavior. He sent a prescription for a sedative, but Mom didn't give it to me. The crisis was over by then.

I don't think Mom ever figured out what I was trying to say that day.

Chapter 4

18 Doctors. Where do I start? Doctors *really* don't get me. Mom's a nurse, so I guess she speaks their language, but they sure don't know how to talk to me.

I've seen dozens of doctors in my life, who all try to analyze me and figure me out. None of them can fix me, so I usually ignore them and act like the retarded person they think I am. I paste on a blank look, focus on one wall, and pretend their questions are too hard for me to understand. It's sort of what they expect anyway.

19 When I turned five, it was time to think about enrolling me in school. So my mother took me to a doctor whose job it was to figure out how smart I was. She wheeled me in, locked the brake so my wheelchair would not roll, and made sure the lap strap was fastened. When my seat belt comes undone—and it does every once in a while—I slide out of that wheelchair like a piece of wet spaghetti.

The specialist was a very large man. The bottom button of his shirt had come undone, and his stomach poked through above his belt. Gross!

"My name is Dr. Hugely," he said in a booming voice.

For real. I couldn't make this stuff up.

"We're going to play a game today, okay? I'll ask you some questions, and you get to play with the toys here. Won't that be fun?"

I knew it would be a long, long hour.

He brought out a stack of well-used, hopefully not lead-tainted, wood blocks, then leaned in so close to me, I could see the pores in his face. Gross! "Can you stack these in order according to size?" he said loudly and slowly, as if I were hard of hearing and really stupid.

But who was being stupid? Didn't he know I couldn't grab the blocks? Of course I knew which block was bigger than the other. But I couldn't stack them if he paid me money! So I just took my arm and swept them all to the floor. They fell with a wooden clatter. I tried not to laugh
20 as he picked them up. He breathed really hard as he reached for them.

Next, he held up glossy eight-by-ten cards with different colors painted on each one. "Tell me when you see the color blue, Melody," he said in that voice that told me he thought this was all a waste of time.

When the blue card showed up, I pointed to it and made a noise. "Buh!" I said.

"Marvelous! Tremendous! Stupendous!" he shouted. He praised me like I had just passed the test to get into college. If I could have rolled my eyes, I would have. Then he showed me green, so I kicked and made a noise, but my mouth can't make the G sound. The doctor looked disappointed.

He scribbled something on his clipboard, pulled out another stack of cards, then said, loudly, "I'm going to ask you some questions now, Melody. These might be hard, but do your best, okay?"

I just looked at him and waited while he placed the first set of cards in front of me.

"Number one. Which one of these is not like the others?"

Did he get this stuff from *Sesame Street*?

He showed me pictures of a tomato, a cherry, a round red balloon, and a banana. I know he was probably looking for the balloon as the answer, but that just seemed too easy. So I
21 pointed to the banana because the first three were round and red, and the banana was not.

Dr. Hugely sighed and scribbled more notes. "Number two," he said. He showed me four more cards. This time there were pictures of a cow, a whale, a camel, and an elephant. "Which animal gives birth to a calf?"

Now, I watch Animal Planet all the time. I know for a fact that *all* the animals he had pictured there had babies called a "calf." I thought doctors were supposed to be smart. What to do? I hit each picture slowly and carefully, then did it once more just to make sure he understood. I don't think he did.

I heard him mumble "cow" as he wrote more notes. It was clear he was giving up on me.

I noticed a copy of *Goodnight, Moon* on his bookshelf. I think it was written in Spanish. It was called *Buenas Noches, Luna*. That would have been fun to look at, but I had no way of telling him I'd like to see the book.

After watching *Sesame Street* and *Dora the Explorer* a million times, and sitting for hours watching the Spanish channels, I could understand quite a bit of Spanish if it was spoken slowly enough—and at least enough words to read the title of that book. He never thought to ask me about that, of course.

I knew the words and melodies of hundreds of songs—a symphony exploding inside my
22 head with no one to hear it but me. But he never asked me about music.

I knew all the colors and shapes and animals that children my age were supposed to know, plus lots more. In my head I could count to one thousand—forward and backward. I could identify hundreds of words on sight. But all that was stuck inside.

Dr. Hugely, even though he had been to college for like, a million years, would never be smart enough to see inside of me. So I put on my handicapped face and took my mind back to last summer when Mom and I went to the zoo. I really liked the elephants, but talk about stink! Actually, Dr. Hugely sort of reminded me of one of them. My mom and the doctor had no idea why I was smiling as we rolled into the waiting room while he wrote up his evaluation of me. It didn't take long.

I'm always amazed at how adults assume I can't hear. They talk about me as if I'm invisible, figuring I'm too retarded to understand their conversation. I learn quite a bit this way. But this conversation was really awful. He didn't even try to soften the news for my mom, who, I'm sure, felt like she got hit by a truck.

He began by clearing his throat. "Mrs. Brooks," he then said, "it is my opinion that Melody is severely brain-damaged and profoundly retarded."

23 Whoa! Even though I was only five, I had watched enough Easter Seals telethons to know this was bad. Really bad. I felt a thud in my gut.

My mom gasped, then said nothing for a full minute. Finally, she took a deep breath and protested quietly, "But I know she's bright. I can see it in her eyes."

"You love her. It's only normal to have wishful thinking," Dr. Hugely told her gently.

"No, she has a spark. More than that—a flame of real intelligence. I just know it," my mother insisted, sounding a little stronger.

"It takes time to accept the limitations of a beloved child. She has cerebral palsy, Mrs. Brooks."

"I know the *name* of her condition, Doctor," my mother said with ice in her voice. "But a person is so much more than the name of a diagnosis on a chart!"

Good try, Mom, I was thinking. But already her voice was losing its edge, melting into the mushiness of helplessness.

"She laughs at jokes," my mother told him, the ice in her voice replaced by desperation, "right at the punch line." Mom's voice faded. What she was saying sounded ridiculous, even to me, but I could see she just couldn't find the words to explain her gut feeling that I had some smarts stuck in here.

24 Dr. Hugely looked from her to me. He shook his head, then said, "You're lucky she has the ability to smile and laugh. But Melody will never be able to walk on her own or speak a single sentence. She will never be able to feed herself, take care of her own personal needs, or understand anything more than simple instructions. Once you accept that reality, you can deal with the future." That was just plain mean.

My mom hardly ever cries. But she did that day. She cried and cried and cried. Dr. Hugely had to give her a whole box of tissues. Both of them ignored me while she sobbed and he tried to find nice words to say to make her feel better. He didn't do a very good job.

Finally, he gave her options. "You and your husband have several decisions to make," he told Mom. "You can choose to keep her at home, or you can send her to a special school for the developmentally disabled. There aren't many choices here locally."

Where do they get those almost-pleasant-sounding phrases to describe kids like me?

Mom made a sound that could have been the mewing of a kitten. She was losing it.

Dr. Hugely continued. "You can also decide to put Melody in a residential facility where she can be cared for and kept comfortable."

He pulled out a colorful brochure with a smiling child in a wheelchair on the cover and
25 handed it to Mom. I trembled as she took it.

"Let's see," the doctor said, "Melody is, ah, five now. That's a perfect age for her to learn to adjust to a new environment. You and your husband can get on with your lives without her as a burden. In time, her memories of you will fade."

I stared at Mom frantically. I didn't want to be sent away. Was I a burden? I never thought about it like that. Maybe it *would* be easier for them if I weren't around. I gulped. My hands got cold.

Mom wasn't looking at me. She was staring daggers at Dr. Hugely. She crumpled up the tissue she held and stood up. "Let me tell you something, Doctor. There is no way in heaven or hell that we will be sending Melody away to a nursing home!"

I blinked. Was this my mother? I blinked again, and she was still there, right up in Dr. Hugely's face!

She wasn't finished. "You know what?" my mother said as she angrily hurled the brochure into the trash can. "I think you're cold and insensitive. I hope you never have a child with difficulties—you'd probably put it out with your trash!"

Dr. Hugely looked shocked.

"And what's more," she continued, "I think you're wrong—I know you are! Melody has
26 more brains hidden in her head than you'll ever have, despite those fancy degrees from fancy schools you've got posted all over your walls!"

It was the doctor's turn to blink.

"You've got it easy—you have all your physical functions working properly. You never have to struggle just to be understood. You think you're smart because you have a medical degree?"

He was wise enough to keep his mouth shut and ashamed enough to lower his head.

Mom was on a roll. "You're not so intelligent, sir—you're just lucky! All of us who have all our faculties intact are just plain blessed. Melody is able to figure out things, communicate, and manage in a world where *nothing* works right for her. She's the one with the true intelligence!"

She marched out of his office then, rolling me swiftly through the thick doors. In the hall we did a quick fist bump—well, the best I could manage. My hands were no longer cold.

"I'm taking you right now and enrolling you at Spaulding Street Elementary School," she announced with determination as we headed back to the car. "Let's get busy!"