

Disjointed

by *Cosette*

The story of a young girl, disabled from infancy, who grows up to be happy with who she is.

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Chapter 1 of 3

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I'm almost ready to start walking on my own when the pain starts in my right knee. I don't want to learn how to walk anymore; I just want to curl up in my crib and sleep.

As months pass, the pain spreads all over my body until moving anything hurts. Eating hurts. Walking hurts. Playing hurts. Even sleeping hurts, because if I don't move at all the pain gets worse. And if I do move, the pain gets worse. My mom and Pa do what they can, but they can't make it go away.

They can only be there for me when I cry.

Life has changed even before I start remembering. Enough baby aspirin for two babies instead of just me. Physical and occupational therapy to try to get my joints moving as much as possible. And the splints, the suffocating pain of those monstrous pieces of molded plastic that are supposed to keep my joints from becoming deformed. When I take them off, I have to snap my bones before I can move again. I feel like I'm breaking my body, one snap at a time.

And while all this is going on, Pa and Mom stop living together and my sister Marcie, the healthy one, is born. She's 16 months younger than me, full of energy, and seems absolutely determined to make the best of her body. She's also fiercely protective of me and never makes me feel bad that I can't play with her. I watch her as if she is just a different version of me. I'm enthralled by what she can do, but it hurts.

She shows me that I'm not normal.

The two of us are sent to a special school, an "integrative" school that plays to parents' dreams for their disabled kids (that's what I am: I even have the parking permit to prove it) by mixing normal and disabled kids, so we learn how to interact with them. It's a great idea, except that all of the normal kids are siblings of the disabled ones. There are no explanations necessary because they all know. But it still becomes my second home.

I love the kids in my class and my teacher. I love the sandbox and the playground. Most of all, I love that there's a kid stuck in a wheelchair in my class, making me feel almost normal. But daily story time, when we all sit "Indian-style" with our legs crossed in front of us, reminds me that I'm not: I'm one of the few kids that can't do it. I try anyways, pretending that it doesn't hurt. But modesty betrays me and I'm encouraged to sit with my legs straight in front of me instead: a visual symbol of failure among the failed.

My mom and my teacher care a lot more about politeness and modesty than I do. I care more about being honest, even if that means I'm not being polite. Everyone always talks about how good it is to be honest; why should being polite be more important? My mom corrects me whenever I answer the question "How are you?" with anything other than "I'm fine". I don't see the point. Why say I'm fine if I'm not? But I'm not supposed to talk back, so I say nothing.

Graduation day here is a big deal. There's a mock stage of two small steps up, a platform, and two small steps down. We kindergarten graduates walk up the steps—most of us requiring some form of aid to do so—to receive our diplomas and walk down. The kids who can't do the steps walk symbolically next to the stage, pausing in the

center to receive their diplomas, before continuing on.

I'm going to a normal elementary school next year. I don't want to leave here, though: at least here, I'm just one of many disabled kids. A normal public school... it's the goal of all the parents and teachers here, to make the disabled kids able to function in a normal public school, to make us able to interact well with normal kids. But here, my disability isn't a big deal. I'm not treated as a tragedy here when adults find out I have Juvenile Rheumatoid Arthritis. I don't have to hear, "Oh, you poor thing," or see the shock of discomfort betrayed in their eyes as they attempt to treat me normally. But I can't stay in kindergarten forever and sending me to a public school is supposed to be what's best for me. That way, I'm not sequestered in with other disabled kids for the rest of my education. That way, I have a chance of being able to function in a world that treats my state of existence as a problem.

The humiliation starts early in first grade. I'm so small that the public school has to borrow chairs from its Pre-First school to accommodate me. I'm followed around from class to class by a spunky aide whose sole purpose is to help me do things the other kids have no problems doing.

By second grade, I'm tired of the staring and the unanswered questions. There's no point trying to hide what the existence of my overly-made-up aide blatantly announces: I am different. There's something wrong with me.

I decide I might as well get it out of the way.

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Chapter 2 of 3

The story of a young girl, disabled from infancy, who grows up to be happy with who she is.

Armed with my joint jailers—my splints—and my mom, I make an announcement to my second grade class. I write in big, uneven letters on the chalkboard the name of my difference: JUVENILE RHEUMATOID ARTHRITIS. I pretend it doesn't hurt just to do that. I explain what it is, how the swelling in my joints—I interrupt myself to explain what a joint is—makes it hard for me to do most things. I show my splints, concrete evidence that I'm not just making this up to get special treatment or pity. (Anyone who's ever received pity, real pity, the kind that diminishes your worth, knows that it's not a gift.) I explain that my aide helps me so I can keep up with the rest of them. And I finish my speech in the same social standing as I started it: as an outcast. But now at least everything's out in the open.

A few days later, I make my first close friend. Her name is Meaghan, and she's as much an outcast as I am. Worse, actually: she's an outcast for no apparent reason. There's nothing physically wrong with her, and the adults all say there's nothing mentally wrong with her either. We kids know better: Meaghan is strange, as if she sees the world at a different angle than the rest of us. But she's loyal to me and doesn't make me feel like a lesser person, so I'm happy to have her as my friend.

There's another girl in my class, though, that I really want to be friends with. Her name is Katie, and I am strangely drawn to her. She's popular, but that's not it: I want to be her friend because she's pretty. It takes me months to gather up the courage to talk to her, but one day I have it.

It's near the end of the day, when everyone is spending a few final moments chatting with friends or packing up their bags. Katie is gabbing with her two closest friends. Meaghan is absent, so I have no one to talk to. Infused with an unusual amount of courage, I walk over to Katie.

"Hi, Katie. Can I have your phone number?" I can't believe these words have come out of my mouth, but they have. Now I just have to wait for her to publicly humiliate me in front of her friends.

"Why do you want my number?" She catches me completely off-guard here; I expected a simple yes or no answer, probably a no, not to be asked my reasons.

I say the first reason that comes to mind, the real one: "Because you're pretty and I want to be your friend."

She smiles, lifting my heart, and then answers, "Well, I think that's a bad reason to want to be someone's friend. But you can have my number."

She writes it down for me. I'm careful not to let our hands touch as she hands me the piece of paper. I never tell Meaghan about this, ever. And I never call Katie, either. She's right, after all: wanting to be someone's friend because they're pretty is a bad reason. Still, for a few moments I bask from the knowledge that I have her number.

Every day at school, the aide follows me around, including into the bathroom. It's the epic humiliation: having an adult go into the bathroom with you. It doesn't matter whether or not the other kids know about it. I know it, and it makes me feel ashamed that I can't even go to the bathroom by myself.

It's not even that I can't use the toilet alone or have trouble getting on and off the seat. I wear spandex pants every day because I can't do zippers or buttons. My only consolation is that spandex pants are somewhat popular, though most of my classmates wear jeans. But there are days when even the spandex pants defeat me. I'm lying here. It's not an unusual occurrence for me to waddle out of the bathroom stall with my pants only up to my knees. Being able to pull up my pants on my own, that's like my birthday, Christmas, and Easter wrapped into one moment. I can exit the stall and tell the aide that I don't need her help. For one moment, I feel the glistening pride of independence.

But most days, my pants win the battle, and I have to exit the stall and pretend not to mind when the aide pulls my pants up for me.

Eventually, Meaghan and I become close enough that she knows that I need help in the bathroom. And since she already knows, and has done me the enormous favor of not telling everyone else about it, it's time for me to ask her the utterly humiliating question: can she help me go to the bathroom? Her face twinges in alarm at the question.

"What kind of help do you need?"

This is almost as humiliating as leaving the stall and seeing the aide waiting there to pull my pants up... but if I can't do it, I'd rather have Meaghan do it than the aide. At least with Meaghan, it's my choice. She wasn't assigned to me by the school.

So, I tell her about the pants. I tell her I can handle my underwear (THANK GOD), but I just usually can't pull up my pants on my own.

And she agrees. From then on, Meaghan accompanies me every time I go to the bathroom. When I leave the stall, pants down to my knees, she just bends over without looking and pulls them up. We never talk about it. We never laugh about it. It's just something that happens.

And the aide waits outside in the hall, unneeded for one blissful moment.

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Chapter 3 of 3

The story of a young girl, disabled from infancy, who grows up to be happy with who she is.

Every Wednesday evening and every other weekend, Marcie and I visit Pa. He picks us up in his white Rabbit, usually more than a few minutes late. It's usually a pretty fun time. We get to do things with Pa we don't do with Mom, like go out for dinner or go to the mall. He's got a real TV, too, with cable. And we get an allowance: two dollars each weekend, one to keep and one that goes into our own savings account.

One weekend, we go to Grandmère's for dinner. A side effect of the handful of adult aspirin I take each morning is that my appetite is pretty non-existent. And, though I don't say anything, my stomach hurts sometimes when I eat. I serve myself a lot of corn, taking the smallest piece of sandwich steak I could. It's not that I don't like sandwich steak, but that it hurts so much to chew. And I'm not supposed to chew with my mouth open, but sometimes I have to. It's a gamble whether or not Pa's going to notice and yell at me. It all depends on whether he's in a good mood or not.

I don't really understand what's going on, but I know both Mom and Pa have lawyers now.

After three spoonfuls of corn, I'm full. I was full after the first bite, but kept eating until I felt like I was going to burst. But when Pa sees my mostly-full plate, he starts yelling.

The world changes. His lips are still moving and that vein in his forehead is pulsating, but I can't hear what he's saying. I say something to defend myself—that I'm full and really can't eat anymore—but the words leak from my lips without sound behind them.

He walks away from the table and tells me to stay right where I am. I just want to freeze this moment or fast-forward until I'm home at Mom's tomorrow. Anything but whatever he's going to do when he comes back.

He storms into the room, brandishing a piece of construction paper like a weapon.

On this paper is a drawing divided by a line down the middle. On the left side at the top are the words "Tania: weak at 38 pounds". Underneath is drawn a stick figure with an IV hanging out of its right arm. On the other side of the paper is a similar drawing of a stick figure, but this one has muscles. And it's titled "Marcie: strong at 55 pounds".

"You have to gain 20 pounds this month or you'll always be weak," he informs me, as if gaining that much weight would be incredibly simple and easy to do.

Frustrated tears burst from my eyes, but I'm careful not to let them stain the paper, this evidence of my weakness.

"How can I gain 20 pounds in one month? I can't do it!"

I sound like a whining baby. I'm a weakling. If I only tried harder, maybe I'd be healthier like Marcie. Maybe I can gain 20 pounds in one month if I really tried.

"That's not enough! You need to gain one pound a day for a month!"

It's just a rage now. I want to believe that he doesn't mean what he's saying. I try to reason with him.

"I can't do that!"

"DON'T TELL ME YOU CAN'T!" He yells, each word slapping my face, injecting me with the knowledge that somehow I'm choosing to be sick.

"Think positive! Do you want to always be sick? Is that what you want?" He points to the drawing of me. "If you don't gain weight, you'll end up like this! Look at Marcie! Don't you want to be healthy like her?"

I ignore the pain in my stomach. It's easy to ignore it now. Maybe I deserve that pain after all. Maybe it's been my choice all along.

I say nothing and start eating the sandwich steak. I let the pain in my jaw punish me.

When he drives us home to Mom's the next night, he puts on a tape especially for me.

"Then make an end of run and hide.

Try to see the sunny side.

Get some joy; you don't have to pay.

The world around ain't only gray.

So let the colors flood your brain:

Feel the light—forget your pain.

If you're not able to believe,

Come on and try to be more...

Positive—it's the better way to live!"

I don't let him see me cry. And every weekend after that one, we listen to that song.

After a month, I only manage to gain 5 pounds. But he doesn't bring it up again, and I don't remind him. I don't need the extra reminder of what a failure I am and how I'm going to grow up to be a sickly person with an IV always hanging out of my arm.