

My Old Bones

A teen speaks about disability

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with Leah Mitchell

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Preface

My younger sister was born with a genetic defect, the effect of which seemed hard to define in our younger days. She attended school alongside me, and she brought home A's and B's. Yet she received detention on several occasions for being late to class. Never one to dash to the ice cream shop between classes or sneak away with friends, she had no explanation for these events. She just seemed to move slowly. She lost things. She failed to notice when the bell rang. She spent a too much time staring blankly into space.

Despite these setbacks, my sister expressed an interest in becoming a teacher, and we (her family and friends) all encouraged her that she could do it. After she graduated from high school, she enrolled in a Christian college and pursued a degree in education. As she had in high school, she kept her grades up. All seemed well until she began student teaching. She failed. We blamed a short-tempered supervisor, and we encouraged her to try again at another setting. She failed again. The school awarded her a degree for her academic success, but they refused to license her to teach in the United States.

Undeterred, we helped her apply for an overseas teaching opportunity. She was accepted, but they sent her home six months into her contract. She found work in a daycare center. Within four months, she was fired.

We finally accepted what should have been obvious all along—that however good her academic success and no matter her excellent intention, my sister simply could not care for young children. She was too slow and too oblivious

to her surroundings. She could not control her tendency to disappear into her own mind and slip away from the world around her. These aspects of her disability did not make her a bad person, but they did make teaching impossible.

Today, my sister works at a deli making sandwiches. She never achieved her dream of becoming a teacher. But she is finally happy in a job more suited to her abilities.

Did you expect this story to turn out differently? Did you expect me to say that my sister overcame her limitations and became the most popular teacher in the school? Modern culture is replete with success stories about disabled celebrities who overcome extreme odds to achieve their dreams. We too often repeat these stories in the ears of disabled people and assure them that if they just try hard enough, they can achieve whatever they want to achieve.

Yet very few of us—disabled or not—can truly achieve everything we dream. And people who struggle with physical or mental incapacity are usually truly limited by these things.

As I reflect on my beloved sister's career disappointments, I wonder whether these events reveal a prejudice in our hearts against disability. Did we put pressure on her to be "normal" simply because we did not want to admit that she would be forever handicapped? Was our own sense of identity so entangled in achievement that we felt that even a woman with a genetic disorder must rise above natural limitations in order to "be somebody"?

These are troubling questions, especially for Christians who know that all humankind is created in the image of God.

Kaylee's story is important because it tells the truth about life with disability—the real struggles, the real disappointments, the real isolation. But this is not a

discouraging tale of bitterness. As we understand the true condition of disability, we can minister to the handicapped in a better way. We can support them in their achievements and encourage them to pursue goals, and yet assure them that no failure or disappointment lessens them in the sight of God or of those who love them.

After all, we are all human and limited by our frailty. All of us grow physically weaker over time. Our value lies not in our own strength, but in the strength of God who redeemed us and made us His own. We all serve God as frail children, each according to the ability He has given us.

Leah Mitchell
February 12, 2015

Carry each other's burdens, and in this way you will fulfill the law of Christ. If anyone thinks they are something when they are not, they deceive themselves. Each one should test their own actions. Then they can take pride in themselves alone without comparing themselves to someone else, for each one should carry their own load.

- Galatian 6:2-5

Chapter 1

Young Face, Old Bones

Doctors are often fond of reminding one another of an old aphorism: *When you hear hoofbeats, think of horses not zebras.* They mean that most people have common problems—a sneeze is probably due to allergies or a cold, not hyper-achoo-osis (or whatever fancy medical name might be invented for some extremely rare sneezing disorder). Medical school interns who spent four years memorizing every medical condition known to mankind tend to want to apply all of that obscure knowledge. They think they see hyper-achoo-osis lurking behind every snuffle. The proverb reminds them that they are unlikely ever to see unusual diseases in their medical practice. They will treat migraines, colds, and high blood pressure. They will x-ray stubbed toes. They will diagnose obesity among patients who suck in their stomachs on the exam room scale as if that really helps. They will explain to some overprotective mother for the fifteenth time that little Ethan’s pimple is just a pimple. But they will probably never ever discover anything that would make headlines in a medical journal. Just plain old horses here, people, no zebras.

Hello, my friends. My name is Kaylee Grace, and I am a zebra. Of course, I am not a literal four-footed beast. I do not prance around a field munching grass like the humbled Nebuchadnezzar. I have a rare medical disorder—Ehlers-Danlos Syndrome (often abbreviated “EDS”).

If you don't know what Ehlers-Danlos Syndrome is, you shouldn't feel stupid about it. Most doctors don't even know what it is.

When I see a new doctor, the visit always begins so well. I don't look sick, and when I'm sitting on an exam table, you can't even tell that my feet are tilted at a slightly odd angle. So the doctor just starts rolling through his usual list of questions.

"Kaylee, how old are you?"

"I'm sixteen."

"What grade are you in?"

"I'm going into eleventh."

"Do you have any allergies?"

"I'm allergic to penicillin."

"Penicillin... uh, huh... okay. Do you ever have migraines?"

"No."

"Stomach problems? Nausea? Vomiting?"

"Nope."

We are just sailing along. For one brilliant moment, he seems so happy. I'm just a normal teen girl in for a physical. One allergy, no headaches, no barfing. He has nearly got it all wrapped up.

"Are you going to play sports this year?" he asks.

Ah, there it is. Whatever form it takes, I can recognize it: the question that will change the tone of this whole visit. Brilliant moment over.

"I can't play sports," I say. "I have Ehlers-Danlos Syndrome."

Doctors react in different ways to this news. But what they never, ever say is, "Oh, right, Ehlers-Danlos Syndrome. I know all about that." No, not at all. They freeze and look panic-stricken. They stare at the ceiling thoughtfully for a

moment, mentally sorting through medical school diagnoses lists that they had disremembered after someone told them about the horses and the zebras. Sometimes, a doctor will even excuse himself abruptly, claiming that he left some important paper in his office.

“He’s going to google it,” my mother informs me. She has had Ehlers-Danlos Syndrome all her life. She knows how it is.

If the doctors never know what Ehlers-Danlos Syndrome is, then I suppose you don’t either. Don’t worry. I won’t make you google it.

Ehlers-Danlos Syndrome is a connective tissue disorder. Connective tissue is the stuff that holds your body together—the glue, so to speak. There is connective tissue in your heart, in the walls of your arteries and veins, between all your bones, and many, many other places. When you have a connective tissue disorder, it can cause all kinds of problems. Some parts of my body are more affected than others. I don’t hear very well, and I tend to stutter when I talk. Occasionally, I faint because my blood pressure drops too low. Those are relatively minor issues. The BIG problem, the one that makes day-to-day life a challenge, is my joints.

Describing the problem with my joints is not easy, partly because my joints have always been this way. I watch teenagers playing ultimate Frisbee in the park, and I wonder how anyone has that kind of energy and coordination.

I am told that my connective tissue is too stretchy, and so my joints are loose and wobbly. My muscles have to work just to hold my bones together. Everything is harder for someone with EDS, they say. Just standing up is a challenge as muscles struggle to hold wobbly bones in place.

In practice, this means that I am slow at everything I do. Standing up is difficult. When I walk, every step is hard. Running is nearly impossible. Climbing is dangerous because my balance isn't good. I'm terrified of heights because I'm always on the edge of falling.

Pain is a constant presence in my life. My ankles hurt. My knees hurt, my shoulders hurt, my hands hurt. I sound like an eighty-year-old woman complaining about her rheumatism, I know. I often feel like an eighty-year-old woman. Well, actually, I feel like a teenager who was built with spare parts—a young girl's pretty face and an old woman's achy bones.

People usually do not think of pain and disability as teenage problems. Teenage girls have pimple problems. They have problems getting their eyeliner symmetrical. They have problems choosing the right dress to wear on a date. In other words, the overwhelming perception of the general population (even in the Christian church) is that teenagers do not have real problems. They do not need special help. No one thinks of explaining to a teenager about the sovereignty of God in trials. What trials could a sixteen-year-old possibly have?

Yet pain and disability are more common among the teenage population than most people imagine. Each case may be unusual in itself. Each young person with a chronic medical condition may be a zebra, but viewed together as a whole, they comprise an entire herd of zebras—teenagers with diabetes, juvenile arthritis, Lyme disease, muscular dystrophy, and other such problems. In any church of moderate size, there is likely to be at least one young person struggling with chronic illness. In my own church of less than 100 people, there are three.

So what is it like to be a teenager with a disability? In many ways, it is very much like being a teenager without a disability. Teens need friends, family, church fellowship, and education. We need to be able to do positive things for others and have positive interaction with others. And we need food. Everybody knows that about teens. Lots and lots of food. We are growing kids.

The needs of teens with disabilities are ordinary, but day-to-day life is more demanding—physically and emotionally. In the next chapters, I will tell my own story, and discuss ways in which teens with disabilities can cope with challenges. I will also present suggestions about how churches can help disabled teens and support them toward becoming full participants in their community.

Chapter 2

The Not-So-Fun Run

My mother jokes that if anyone wants sympathy for a disability in our family, they have to stand in line and wait their turn. Everybody in my family has some sort of chronic disability. My dad is the healthiest—he has diabetes. Even with that problem, my dad is a big, strong guy, and he is very good at taking care of people—which is a mercy, because we all need him. My older brother Kevin is autistic. My mom and my little sister Sydney both have Ehlers-Danlos Syndrome like I do.

My mom grew up with many of same problems that I have—aching joints, fainting spells, and general weakness—but she did not know what it was. Her family thought she just needed more exercise, and they made fun of her for being so tired all the time. Maybe that is why my mom is such a fighter for me now.

Mom's EDS is worse than mine, and she can hardly walk a straight line on a good day; but on the inside, she is tough as nails. I mean, don't get me wrong—she loves me, and she loves my brother and my sister and my dad and all her friends, so she is soft in that way. But if she thinks someone is hurting one of us, she will hunt them down to the ends of the earth to break their legs. Okay, not really, but I always get the feeling the only reason their legs are still intact is because she is a Christian.

My mom used to be a math teacher before she became too disabled to teach. She loves statistics and calculus and all that stuff. Maybe it is in her genes, because I am good at

math too. When I was in 8th grade, I was already in Honors Algebra. Next year, I'm starting college classes for math.

It wasn't always like this. In fourth grade, I couldn't add or subtract much, and I definitely couldn't multiply or divide. Well, I mean, I could, but I was really slow about it. I couldn't remember the answers. I had to count them out on my hands again every time, so it took forever. The other kids would be finished with a test, and I would still be on the third question.

When my teacher found out that I didn't have my multiplication tables memorized, he stared at me like he was wondering what I had been doing with all my time. I wanted to crawl into a hole to hide. I was sent straight to remedial math, which, if you don't know, is math for kids who can't do math (to phrase it politely). Remedial math was okay. The teachers were nice, but the material was boring, and by fifth grade, I still didn't know my multiplication tables.

Math wasn't my only problem. Gym was practically torture. Twice every week, I marched tearfully down the hall with my class on my way to the chamber of horrors that was the gymnasium.

It wasn't that the gym teacher was mean. I actually liked him. But the activities themselves were hopeless. I couldn't run. I couldn't jump. Balls that were thrown at me just hit me in the face. I couldn't even get out of the way fast enough, so I got run over by other kids.

The worst event was the annual ironically-titled Fun Run. There was neither fun nor even much running involved for me. Kids in first through fifth grade all gathered at the starting line with the course marked out ahead of us. The coach yelled, "Go!" and the whole herd lumbered forward.

At the beginning of every Fun Run, I would tell myself that this would be the time I kept up with the rest of the class. I could do it this time! The spirit was willing, but the flesh was weak. After a few seconds, all my energy was spent. I dropped to a walk. Kids three years younger than me passed me by in a flash. I tried to gather my strength to trot a little more, but soon it was obviously hopeless. From the halfway point on the course, I could see the other students had all crossed the finish line. There was nothing to do but keep going—a long stretch of humiliation with the whole school staring at me as I limped slowly down the remainder of the track. To their credit, the other kids never commented on it, but I still felt very embarrassed.

If my challenges at school had only been in math and gym, I might have survived elementary school better. Those two things stand out as particularly problematic, but the truth is that each day was sort of a disaster unto itself. Every day was a Fun Run from the moment I stepped in the door of the school. I would begin each morning determined to make this day work better. I would keep up with everyone today!

But it never happened like that. I was too tired. Everything was so much work. With my hearing problems, noise in the class confused me. My brain had to work hard to listen. The constant standing up and sitting down, getting in line, walking here and there, writing, counting... it all took a toll. Within the first few minutes of the school day, I was already tired. By 10:00 am, I was lagging behind.

By the time we were getting ready to go home, I couldn't remember what my homework was, and I was too tired to care. I left my lunchbox, my homework, and my jacket. I just wanted to go home.

By the beginning of fifth grade, I had already been in remedial math for a year, but that was no longer the only problem. Bad grades were routine. Homework went undone most of the time. Even when I did my homework, I forgot to turn it in. I had given up. I had already seen the rest of the class crossing the finish line ahead of me and I knew I could never compete. It seemed like it didn't matter what I did or didn't do. I might as well sit down at the starting line because my chances of succeeding if I did nothing were the same as my chances of succeeding if I threw my whole heart and soul into the race: no chance at all.

I would never claim that my experience in elementary school was particularly bad. Some kids have stories about getting beaten up at school or other kids making fun of them. Nothing of that sort happened to me. This is not a pitiful tale of outrageous bullying. In fact, I hope my story is more helpful to average disabled people because it is so *normal*. It is exactly the sort of frustration and discouragement that is faced by disabled kids every day, *even when people mean no harm*. My teachers were genuinely nice people, and they tried to include me. What they never seemed to realize was that inclusion was doomed from the start. Their entire plan of action was founded on mistaken ideas.

Education has a lot of fine-sounding slogans: "Who cares whether you win or lose as long as you have fun?" and "You can do anything you put your mind to!"

The truth is that you can't have fun when the whole school is staring at you, watching you lose. And you can't do anything you put your mind to. You just can't. Sometimes you try your best but fail because you can't

remember things or you aren't strong enough. My mom says that sometimes the better part of wisdom lies in realizing that you can't build a tower that reaches to the heavens.

Only God can do anything He puts His mind to. The rest of us are mortal. And some of us mortals were born disabled.

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