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Girl, Interrupted

The Accident

*Tell me the story
'bout when you were young
Leave in the part
where the hero gets stung
(Annie Lennox, "Lost")*

On a scorching afternoon on June 4, 1976, my mother gave me the choice between catching the school bus to go home to our farm after I was finished with my school day or waiting a few extra minutes for her to finish up her meeting with the Catholic Women's League that was happening across the street. Although I was only six years old I had enough experience riding the bus to know that the long ride home would be uncomfortable, sweaty and hot. I decided to wait for my mom. Besides, I did not want the older kids on the bus to tease me about what I was wearing like they had in the morning.

A few days earlier, a boy in my class told me that I was not like the other girls because I never wore dresses and that if I wanted to be pretty I had better start wearing some. So on this hot, sticky day, I wore a simple lavender gingham cotton dress and as I waited for Mom to pick me up and take me home, I was impressed and surprised with how much cooler a dress was than my usual blue jeans. Nevertheless as my mom, my older sister, Joanne, and my niece, Kirsten, and I drove home with all the windows rolled down in a wishful attempt to bring some relief the way only a cool breeze can on that kind of sweltering day, I lay down in the backseat of our car and imagined how good a cool lemonade would taste under the shade of our garden's crabapple tree.

My day dreams were interrupted by what I can only remember as a chaotic mix of images: my mother's head cut and bleeding; strangers talking in loud, urgent voices; the sound of my sister crying and feeling pain and discomfort from a sheet of cardboard behind my back and shoulders that someone had laid me on. I can still feel the asphalt underneath my fingers.

I could hear Joanne crying. My mom was frantically looking around for her lost earring; meanwhile with a strange calmness I realized I could not feel my legs. When I told my mom this, she explained to me that I was in shock. Although I do not know how my other family members learned about the accident, I remember my dad arriving on the scene, and how my brother Jim leaned over me to offer encouraging words.

The next thing I remember is a cold, brightly lit emergency room where I was again lying on my back and feeling extreme pain. When I overheard the doctor tell my mother that my dress would have to be cut off because he could not risk doing damage to my body while pulling it over my head, I screamed and cried. While I could not feel my legs, while I was experiencing excruciating pain in the places I could still feel, surrounded by strangers in a strange place and knowing instinctively that something was terribly wrong with me, my most prevailing thought was how I did not want that dress to be mutilated by a pair of scissors. I honestly remember thinking, “How will I ever be pretty again?” In my mind, that dress meant I was a girl. In that moment, the idea of losing that identity was somehow more tragic than what my body was experiencing.

Where's the Girl: Lowered Expectations

*It's just your expectations
should be lower
(Edwyn Collins, “Low Expectations”)*

Ironically, my grief over the dress's destruction was a foreshadowing for how my identity would also alter. As a girl with a spinal cord injury who uses a wheelchair, I experienced a markedly different set of developmental, social and biological expectations than non-disabled girls my age seemed to experience as they grew up. For example, it was assumed that I would always need someone to look after me; that I would not live independently; that I would not be able to attract a man, date, marry; and certainly not have a sexual relationship, have children, and be able to look after those children. Because my spinal cord was injured at a young age, I believe this expectation that I would live a socially and sexually barren life was even more poignant for me than for women who acquire their disabilities later in life. At age six, I had not yet, of course, developed sexually in either physical, social or emotional ways. I was just simply too young. Women who acquire their disabilities later in life may still struggle with their identities, but generally they have had more time and opportunities to develop their sexuality.

French philosopher Michel Foucault describes social forces, especially those associated with sexual identity, as strong influences on how we define

who we are and how we present ourselves.¹ Feminist writer Judith Butler argues that there are societal expectations of men and women that are “accepted” ways to “perform” gender, such as women as nurturers.² While I think she is correct, I think that there is also a gendered experience of disability that assumes that to live with disability is to live without sexuality.³ The asexual status that is often attributed to people with disabilities was, I believe, stronger for me than for other people who are injured after they have achieved their sexual identities, because, unlike people who experience spinal cord injuries later in life, I had no opportunity to develop an “adult” construction of sexuality or the pre-pubescent or adolescent constructions of sexuality. After a spinal cord injury, sexual identities and adult social roles are often denied.⁴ When my spinal cord was injured, part of my identity as a girl was ruined too, just like the remnants of my lavender gingham dress.

Having my spinal cord injured and becoming a paraplegic so early in life, I did not have many chances to achieve much of a sexual identity and there were no expectations from most of the adults in my life, such as family members, teachers, friends and neighbours, that I ever would. There were none of the comments that my peers received, like, “Heather will be a heartbreaker” or “Heather will be a good mommy someday.” Growing up with the unspoken yet prevailing attitudes that I would not live a fruitful and productive life, that I would not live independently from my parents, or become anyone’s employee, girlfriend, wife or mother, became undeniably, consciously and subconsciously, ingrained in how I identified and saw myself. It was more acceptable and easier for me to see myself, and to be seen by others, as a “cute kid,” which is a more androgynous and asexual label, than as a “pretty girl,” which is decidedly more feminine and by consequence, sexual. I seemed to be surrounded by pretty classmates and cousins. I was always aware that wheelchairs were not pretty, and since I associated myself with my chair, I thought I could not be pretty either. My desires for feeling as though I were a pretty girl led into confusion about my feelings of sexuality as I entered my teenage years. If I was not pretty, then I could not be sexual, and if I was not sexual, then I was not a real woman, or a whole person.

This does not mean I did not try to be pretty. I styled my hair, I wore the fashions of the day and I used makeup. But I did this mostly with the intention of proving to everyone that I was a “real” girl. I ached for the validation. Throughout dating, my first sexual experiences and even marriage, I made steps towards realizing my own intrinsic worth as a sexual person, but in the end I did not realize how much I had internalized the notion that to live with a disability is to live without sexuality until I became pregnant for the first time. It was then that my sexuality could no longer be denied by anyone, not even me.

August 18, 1996

I just don't know how to feel. I have to go to the bathroom a lot and every time I do, I expect to find the blood stains of my period, informing me that this whole thing has been a huge misunderstanding. It's not that I don't want this baby; I just can't believe it is happening. Could something this natural, this normal, really be happening to my body? My body that has never been my friend. The bottom line is this: I did not expect I was ever this female.

I remember yearning for my period when I was about twelve or thirteen, as I know many girls that age do. *Are you there, God? It's Me, Margaret*, the coming-of-age novel by Judy Blume whose main characters were obsessed with bras and first periods, was so popular among my classmates that it was impossible to sign out of our school's library. Desperate for this rite of passage, I think I felt the same way as the characters in that book and my friends did. As it happened, my period came in my mid-teens, and although this is perfectly normal, at the time I was sure the delay was because of my paralysis. My paralysis was responsible for everything. That notion, as irrational as it might seem to me now, stayed with me for years. So once I was married and Darrell and I knew we wanted a family, we did not know if my body was capable of getting and staying pregnant, or delivering a baby. As well, unlike our other married friends, no one ever asked us when or if we were going to start a family. The assumption was that we would not or could not get pregnant, so no one asked. We decided to try and get pregnant, but if I could not conceive (again, I thought if that was the case it would be because of my paralysis), we would adopt. So when I missed my period in August 1996, I did not think I could be pregnant. My friend, Pam, who is a nurse in my doctor's office, convinced me I needed a pregnancy test, and bet me a milkshake that it would be positive. Obviously, I lost that bet.

Home Girl

*Saturated with negative images
and a limited range of
possibilities is strange
(Shad, "Brother")*

In the early months after my injury, it was suggested by my then rehabilitation doctor and the rehabilitation centre's head nurse that I would be better off living and going to school at the Children's Rehabilitation Centre in Saskatoon (an hour and a half drive away from my home), at least for a while, lest, in their opinion, I become too much of a physical, emotional

and financial burden on my parents. At the time, the construct of disability was primarily dictated by a “medical model” that saw disability as a pathological problem that resided in the “patient” and required the solutions of rehabilitation and medical intervention to correct his or her “deficiencies.”⁵ The scientific system that underlies the medical model has certainly brought about medications and other technologies that improve physical functioning for people with disabilities; however, many more difficulties for people with disabilities reside within the social contexts of disability.⁶ This was definitely true for me and my parents. Whereas my parents and extended family wanted me back at home and found it relatively simple to add an outside lift to our house and renovate our bathroom to include grab bars, it was considerably more challenging to weave me back into the social systems of school and our community, where oppressive and negative stereotypes about disability were firmly ingrained. It was, for example, easy for me to make friends, especially with those who were curious about the wheelchair. But it was also difficult for me to retain those friends once my disability was noticed by other peers who chose to tease or make fun of me. I would quickly become someone who was a threat to my friend’s social currency and I would be dropped. As I reflect on my childhood friendships, I realize that I certainly had some true friends who were loyal to me, but I did not feel secure in those friendships. Indeed, I was often afraid of being left alone. I wanted to belong, to fit in and to feel welcome.

There were times when I was consciously included in my community. My elementary school principal made sure that I was welcome back in my school. A ramp was constructed, my desk with the built-in seat was swapped for a table and the girl’s bathroom was modified. But when my best girlfriend joined after school clubs in another part of town, and I was told I could not join because there were steps to get in, I was sad. When I attended her dance recitals and saw her in her beautifully embroidered Ukrainian dresses, I was delighted to watch her dance, but heartbroken because I thought I never would. It was not that I necessarily wanted to be a Ukrainian dancer like her; I just wanted to feel like I was a part of something too.

Watching your child struggle socially is difficult for any parent and mine were no exception. At the same time, they also were without real-life examples of other people like me and like themselves. In other words, not only was I without expectations and social norms, so were my parents, and therefore they were also without imagination for what the rest of my life would be like. Psychotherapist Rhoda Olkin argues that “there are so few role models... that parents often have no vision of what their children can become.”⁷ My paralysis and the uncharted territory of my new disability-related needs seemed to overshadow everything else that I was or could imagine becoming.

As I wrote this book, the following parts about my childhood and the

stories of my parents (especially those of my mom), became intertwined. My mom was saddened after she read my manuscript the first time. There were things she read that I had never told her about before. It was never my intention to cause her pain and although I have not altered this manuscript or changed the stories, I want to make one thing clear: I love my mother. Although my mom was not perfect, and although there were things I wish she had done differently, who among us has not felt that about our parents? My children are still young, and yet I often lie awake at night and ask myself if I am doing a good job or if I am measuring up as a parent. I usually come to the conclusion that I am doing the best I can. While I cannot imagine how hard it was to raise me, what I know for certain is that my mom loves me and that she did her best. In fact, without anyone to turn to, without any sort of guide, she did much better than that. Both of my parents were strong and brave at times when it would have been easier to give up.

It's a Girl Thing: Longing for Long Hair

*She never really expected more
That's just not the way we are raised ...
She's looking in the mirror
She's fixing her hair
(ani difranco, "Fixing Her Hair")*

In the fall that I returned to school after the accident, this time sitting in a wheelchair, wearing pants and sporting a pixie cut, I remember expressing to my parents that I wanted to grow my hair longer so that I could wear “pony tails like the other girls at school.” My mom encouraged my short hair, explaining that short hair was easier and that I had “enough problems without having long hair to look after, too.” I was hurt then, but I do not blame her for feeling this way now. I do not doubt that if she had known how much it meant to me she would have let me grow my hair, but I did not push the issue. I remember feeling the need to protect my mother from further sadness very early after the accident. I know that she also had strong feelings of protection towards me and that she was doing her best to care for me. It must have been intensely difficult for her to do all the things for me that she was required to. I think about this long hair dilemma that my mom must have faced every time I now wash my own daughter's hair and painfully have to comb through her tangles. Perhaps my mom was speaking to the exhaustion she faced being both my mother and my primary caregiver (she was, after all, responsible for all my physical needs at this point — from physical therapy, to lifting me in and out of bed, to transferring me in the bathroom and doing all my catheterizations), and combing through

hair tangles was just one thing she could not add to her already long list of obligations. Or perhaps she was reluctant or even fearful to see me resemble a girl and all the complications that came with that (like boyfriends, dating) in addition to the identity of disabled, paraplegic and needing a wheelchair.

Parenting is an incredibly difficult job. I think it was even more difficult for my parents, especially my mom. It is difficult for her to talk about the accident and my childhood because she still bears personal responsibility for what happened. I do know that it was difficult for her to allow me to move through the rites of passage that other girls my age were experiencing. I am sure it is difficult for any mother to watch her daughter move from child to adolescent but, although I know she was doing her best, I think it was especially hard for mine. Without knowing what kind of a future existed for me, without any models or examples for her to look to for hope or inspiration, and with a deep sense of responsibility for my bodily care, I think my mom viewed me, at least at times, as weak, dependent and helpless. She once confessed to me that she used to lie in bed and wonder what I would ever do without her. Fair enough. She had to do so much for me. She also had no idea what my future would be like. The only people with disabilities she had ever really been exposed to were elderly or in need of constant care. These characteristics are how people with disabilities are often seen and they are the opposite of how a mature, sexual person is seen, which is typically as strong, self-reliant and physically competent.⁸ As an adult, I often marvel at how difficult it must have been for my mom, and how strong she was.

It's a Girl Thing: My First Bra

When I was twelve or thirteen years old and aware that other girls were starting to wear bras, I expressed that I wanted to wear one too. In my mind, this garment was a significant mark of a “real” girl. My mom was reluctant to purchase one for me, telling me that I was “not ready.” She was probably right — my body was likely not in need of one. However, afterward, I felt ashamed for asking and I did not mention it again. Instead, I frequently left the Sears catalogue open to the bra section on the end of my bed, as a hint and subtle reminder. When she finally gave in to my unspoken pleadings and bought me a bra, it was not made of the shiny, satiny and stretchy material that my cousins and friends were so proud of wearing. It was plain white cotton and I was disappointed. I wanted what I imagined everyone else had. I wanted a pretty bra because receiving it would have been recognition that I was a pretty girl who was growing up. I remember wearing the bra anyway and the first time I had it on at school, with the outline of those telltale straps showing through my t-shirt, certain that everyone noticed and was talking about it. I imagined they were surprised that I had one on and that they were thinking, “Heather is just like everyone else.”

Foucaudian analyses state that social forces, especially those related to sexuality, have an intense influence on how individuals represent themselves. Foucault would also say, however, that when these forces are exerted, resistance to the power of those forces may also occur.⁹ My desire for a pretty bra was much stronger than my sense of obedience towards my mother. In an act that resisted the power of my mother's act to provide me with the kind of undergarment that I thought exemplified prettiness and sexiness, I bought my own bra at the local Kresge's store with some saved birthday money. I chose it off the shelf and then hid the small box it came in between a paperback novel and a chocolate bar. My anxiety that someone would catch me and tell me that I was not allowed to buy it made my breath come in short gasps; however, once I paid for it and hid it in the shopping bag, I relaxed a little. I had no idea how I was going to keep it as a secret from my mother once it was home in my dresser drawer. The entire act was worth it once I arrived home and put on that bra, that bra that was just like the one that the other girls were wearing. While my mom was trying to exert control over what she thought I should wear, I was exerting a reciprocal power by demanding a part of my identity that I was desperate to claim. Perhaps I was also frustrated with how many times I missed out on the many social constructions that seemed to happen naturally for my female peers: I did not wear dresses, I did not wear my hair long and, although I attended all my junior and high school dances, I was not the girl that anyone ever had a crush on, I very rarely danced with a boy and I did not date. There were other more subtle markings of what it meant to be a girl — the way they moved, walked, stood, danced, and sat with their ankles crossed. The purchase of a bra was something I could control, although the act came with the threat of shame and anxiety. However, I had what I wanted and, at least in one small way, I felt like a "real" girl.

It's a Girl Thing: Dresses

*If I don't want to, I don't have to
I don't have to wear a dress
I can sit with my legs apart
(Betty Blowtorch, "Dresses")*

I chased my sense of feeling female for years; some days I think I still do. I still feel a twinge of displacement and a little bit of shame when I shop for lingerie. For me, symbols of femininity were tangible objects that were external to me and that made sense to a little girl: long hair, bras and dresses. After that precious lavender gingham dress was cut off of my small six-year-old body that day in the Emergency Room, I do not remember wearing a

dress again for three years. By then, I was marking my ninth birthday at the Hospital for Sick Children in Toronto, where I was a patient.

I had arrived at the Hospital for Sick Children because my mom had read about the advancements that this hospital and its neurosurgeons were making towards spinal cord injuries research. She bravely picked up the telephone from her farm house kitchen in small town Saskatchewan and dialed one of the doctors in Toronto she had read about. Astonishingly, the doctor told her to book a flight and bring me to the hospital and he would take me on as a patient. One of the first things the medical staff did for me was remove the indwelling catheter with the leg bag that was strapped to my calf and subsequently taught me how to do independent, self-catheterizations, a process they promised me and my parents would add years to my life by ensuring fewer bacterial infections and less stress on not just my bladder but also my kidneys and overall blood stream. But from a nine-year-old's perspective, it also meant that the ugly, embarrassing and smelly leg bag would be gone and because my legs would be free and bare, I could wear a dress again. I was excited about this idea. Mom and Dad went out and bought me a dress for the birthday that I celebrated as a patient, and I remember the special event of unwrapping it in my hospital room at SickKids. Although I no longer have it (I wish I did), I can picture it vividly: it was buttery cream-coloured soft cotton with a lilac paisley trim. It even had a bow in the back. Dad admitted to me that no one would be able to see the bow when I was sitting in the wheelchair, but because both he and I knew it was there, that was good enough. I loved that dress. And I loved my parents for buying it for me and for somehow understanding that the dress could give me something I was missing: a sense of being ordinary, feminine, pretty and therefore, in my mind, valuable, beautiful and whole.

Dresses continued to be an important symbol of my female identity into my adolescent years. For example, I desperately wanted to wear a dress to my first junior high school prom. My mom seemed resistant, telling me that because I could not cross my legs nor keep my knees together while sitting in the wheelchair, that a dress was not the best option for me. There was an unspoken "girl" rule that to sit in a dress with your knees apart meant an increased potential for exposing something that best remained covered up. This risk of exposing of my private area, an area that is inherently sexual, only served to further confuse me. On one hand, I received the message that my disabled body rendered me an asexual being; on the other hand, I was also being told that the dress could expose that which made me sexual. Nevertheless I still wanted a dress. I know Mom sensed my disappointment and as she was a skilled seamstress, she offered to make me a "nice jumpsuit" out of whatever fabric I wanted. Eventually, however, I was either persistent or outwardly depressed enough that she gave in to my desire to look pretty

and feminine and Mom sewed me a dress to my first prom, just like the other girls. Like the other significant dresses in my life so far, it was also a shade of lavender. It was also cut in the brazen style of the mid 1980s. It was made of taffeta, had a fitted top and huge puffy sleeves that were in the off-the-shoulder style of the day. Underneath the shiny taffeta skirt of the dress, I duct-taped my knees together and I felt like a princess. I went to the girl's bathroom midway through the dance. It was jammed with girls competing for mirror time, combing their hair, applying makeup and adjusting their dresses. I was so proud of my beautiful dress. I had received so many compliments on it and on how it looked on me. I was about to leave the hustle and bustle of the bathroom when a girl I knew quite well exclaimed that the back of my dress was so low that it showed my surgical scars. There was no mistaking the shock and mild disgust in her voice. Thunderstruck, my humiliation grew as the girls crowded around me, wanting to take a look at the scars that were peeking out from the back of the bodice.

The event was not the first time that I would be ashamed of my physically different body at school. Although many efforts were made to integrate me in the classroom with my non-disabled peers, once I was attending junior high, I did not take part in many of the physical activities that boys and girls my age were involved in, including the physical education programs. No attempts to modify a program were made for me. I was often required by the teacher to change out of my school clothes and wear a gym uniform as I watched my non-disabled peers from the sidelines during physical education class. I went to the locker room and changed into the gym shirt, along with everyone else, and then I would sit and watch the class. I dreaded entering that locker room; I felt ridiculous. Yet, it was a ritual that everyone else participated in, so I continued to do it without question. I do not remember anyone else ever questioning it either. I remember one time when a teacher had me try some free weights off in one corner of the gym while my classmates played volleyball. However, I was even more self-conscious then, like I was sticking out even more than sideline-sitting. In this half-hearted attempt to involve me, I also felt like an imposter, like someone who did not deserve to be there, which was inevitably worse than just watching.

Shooting Like a Girl

At the same time, however, our visit to the Sick Children's Hospital in Toronto opened my parent's eyes to the benefits of physical activity. The medical specialists there encouraged Mom and Dad to involve me in any kind of activity that would get my body moving. The benefits, we were told, would be better blood circulation and lower risk of heart disease and diabetes. They also felt it would improve my feelings of self-worth and lower my risk of depression. In particular, Mom and Dad were motivated to have me try

swimming. Because the local swimming pool was not accessible in many ways, (I remember not being able to fit my wheelchair into the change rooms) and because my parents never did anything halfway, they researched, designed and built an indoor swimming pool right outside my bedroom door, and swimming became a daily activity for me.

At the same time, spending time outdoors, sport and physical activity were also integral parts of my family's life. Although I was an active little girl before the accident, with my girlhood interrupted, priorities for activity changed. Leisurely sunshiny playtime on the farm amongst the crabapple trees was replaced by a lot of time spent indoors and my childhood became complicated by bladder infection prevention, healing pressure sores, physiotherapy and regular doctors' appointments in the "big city" of Saskatoon. My family made conscious efforts to include me in the fun I had always been involved with before my injury. My parents and my brothers took me snowmobiling, sledding and even skating. My brothers Ernie and Jim fished and would often take me with them. They would carry me in and out of the boat, leaving my wheelchair on the shore. I loved watching my wheelchair get smaller and smaller the further we went out into the lake. We once watched as my chair slipped from a steep embankment into a river. We did not know whether to laugh or cry as Ernie jumped into the water in a successful attempt to retrieve it. I vividly recall how scared my niece, Tanya, was at the idea of losing my wheelchair, and how I did not care nearly as much as she did that I get it back. We all laugh about it at family functions now.

Furthermore, both Jim and my dad were national team athletes (my brother-in-law, Errol, was also an active competitor) in the sport of target shooting and I would often accompany them on trips to competitions; but, just like all my other physical activity and education experiences, I was left to watch from the sidelines. Coincidentally, around this same time, my dad met Richard, a small-motor mechanic who was a paraplegic. Knowing my dad's athletic history, he asked for some help in learning how to shoot. My dad provided him with equipment and some coaching. Once this fellow paraplegic started competing, Dad asked him if he knew of any young girls in wheelchairs who were involved in the sport. The answer was that there were not many, especially in Canada, but, nevertheless, this inspired Dad to encourage me to try. As it turned out, I had plenty of skill that surprised everyone, especially me. I loved shooting and it was a boost to my confidence that I was good at a sport. I was sixteen years old, it was 1986 and I attended several matches that year in competition against my non-disabled peers. While at Nationals that year I was approached and encouraged by Olympic gold medalist, Linda Thom, to try wheelchair sports. "You could be a Paralympic gold medalist," she told me. I retorted, "I plan to be an Olympic gold medalist, actually."