

# Hidden in Plain Sight



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## My Sister and I

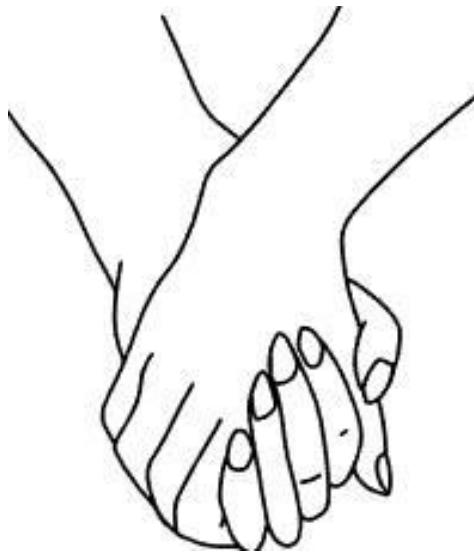
My sister and I share the same invisible disability, yet we have been treated differently for it our entire lives, with my own being regularly validated and even normalized, while my sister has been told to ignore it or that it doesn't even exist. As insinuated by the name, our disabilities and, subsequently, our pain is not seen with the naked eye; Jane McLeod makes note of this unavailable image. She recognizes that "invisible disabilities typically receive less attention in the sociological literature on disability than visible, physical disabilities" (McLeod 8). I have never seen the disability I share with my sister on any page in any book I've read, though I have *seen* it represented in TV shows and movies, though it is often used in a joking way. Visible disabilities are also expressed using ableist caricatures, but they are given visibility on a larger scale than those that are hidden in plain sight.

Living in our world with an invisible disability is challenging. My sister and I experience ableism from others, but it is not the sort of ableism that one typically associates with disability. You can't *see* what is different about us, but sometimes the symptoms manifest on the surface—which we try our best to hide for fear of judgment in most cases. Alaina Leary understands what it's like to live with an invisible disability, having to go out into the world only to be faced with skepticism about our bodies. She, like many, recognizes that the "world wasn't designed for disabled people, and when your disability isn't as visible, you're not only experiencing ableism and fighting for accommodations, but you're doing so while having to constantly explain your disability to those around you" (Leary). Our disability essentially makes us invisible, forcing my sister and me to constantly identify ourselves, if only for a minuscule amount of understanding from others. The only other person in our lives that understands our pain is our maternal grandmother, who personally struggled with the exact same ailments over the course of her life. She, like us, hides her pain behind an air of comfort that never truly exists for our bodies. Even hidden, though, there is a bit of safety, away from prying and judgemental eyes; if they don't know that the pain is there, they can't assume that it is a lie.

People can sometimes want to immediately judge us as false, as though we are committing a crime with our bodies. These same people often feel the same about those who have visible disabilities, but they are often more guarded, even unaware of their opinions toward their bodies. Visible disabilities are easier to spot than those that are invisible, making it easier to "categorize that person" than those whose "invisible disabilities are not immediately recognizable" (McLeod 13). Even though my disability was as invisible as my sister's, she received a harsher categorization than I ever have on account of her silence on the matter; silence, in the way that one doesn't defend themselves, even as the invisible becomes visible to others. My sister should not have had to defend herself from the judgment of others; that was our parents' job, and they failed miserably at it. My sister received judgment for her disability from others, even her own teachers, contributing to her dislike of the education system on account of her not being entirely safe within such environments. In truth, my sister was set up to fail the very second her disability was questioned by others, and when I say 'fail,' I genuinely mean it. It is crucial to keep in mind that "inequality has its roots in the interaction between persons and institutions"; institutions like our

parents, her teachers, and even myself on occasion (McLeod 21). My sister endured trials and tribulations that I have not, and because of that, we have both had varying degrees of happiness throughout our lives that are directly related to how people have seen us.

Zawn Villines broaches the topic of ableism and how it varies from person to person. Even though my sister and I knew the same pain, others did not perceive it as such. Ableism in our society “affects people differently depending on how others perceive” disability, whether visible or invisible (Villines). At the end of the day, the only sure-fire difference between me and my sister is that I have never been silent about my pain. In the words of Anne Werner, “the only difference is that I complain more,” but my sister—in her silence—became “the person who has pain because [she needed] to have pain”; her body became villainized as though she was responsible for her pain (1035-36). My pain was taken seriously because I regularly expressed it, while my sister’s was ignored in favor of protecting me, and the toll that took would have extensive consequences as we grew to become sisters.



## She Cries Too Much

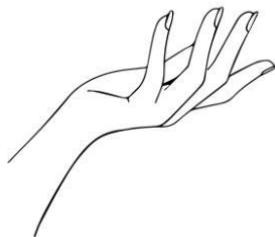
“Why don’t you just feed her?” Our mother was always asked this critical question by almost everyone around her when I was born. As though she didn’t *try* to feed me, only for me to force everything back up and onto her, that wasn’t the hard part. My sister—her first daughter—had done the same thing, though with a far less obstinate attitude; well, she didn’t scream as much. We were both born with fire in the pit of our stomachs, burning at the roots of our throats and causing significant pain to the two of us, but only one of us cried because of it.

My sister didn’t like me all that much, at first, though mostly on account of my incessant whining. I kept the whole household up, day in and day out, always in pain and letting everyone know about it.

“Why does she cry so much?” My sister always asked our mother this, trying to understand why I couldn’t keep my mouth shut. Mom would answer with the typical ‘she’s just a baby,’ and Dad would simply parrot her. My pain was a tad more visible, but it still took some time for me to be more than *just a baby*.

Two months after I was born, our parents took me to a doctor; they were concerned about my pained crying. After the appointment—and a bit of poking and prodding—I was diagnosed with a condition called non-esophageal acid reflux, which, in basic terms, means that the acid in my stomach boils at a higher rate than most other people. Even with a diagnosis and a change in formula, the pain continued, though with my parents’ attempts to control it. Throughout all of this, our parents never thought to consider that Taylor might have had the same ailment, even though she’d had the same difficulty eating when she’d been my age, even though it was a genetic disorder that the two of us shared with our maternal grandmother. All the same, she was ignored simply for not expressing her pain in a visible manner.

My sister was three when I was born, so she wasn’t entirely aware of me on a more personal level, especially since I’d only just entered the family. Our relationship started later as we grew, but I never stopped crying, and she never started crying until well into her later, more current years—when the pain became unbearable, and she could no longer mask what had plagued her for her entire life.

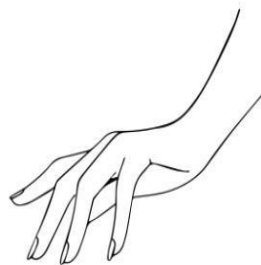


## Disciplined Into Silence

Our parents ignored my sister's pain in favor of recognizing and even normalizing my own. As a result, my sister had been essentially disciplined into a state reminiscent of what the French philosopher, Michel Foucault, recognized as docility. Foucault expressly defines docility using allusions to the human body as well as to imprisonment, stating that a "body is docile that may be subjected, used, transformed and improved" (136). My sister was subjected to constant distrust by our parents, used as a lesser example in comparison to me, and forced into ignoring her own pain for the benefit of everyone else in the family. There is one aspect that clashes with Foucault's concept, and that is the idea of improvement. My sister's bodily pain did not improve—go away—nor did she completely abide by the discipline our parents tried to instill in her; they had an easier time forcing docility onto me than her.

My sister and I believed that we had been raised differently, which could explain the differences in our personalities. However, considering Foucault's teachings, I have come to the realization that we *do* share a significant factor in our upbringing. Our parents wanted us both to grow up as docile individuals, willing to forego our own autonomy for the sake of our domineering parents. Under the will of our parents, our bodies became other to us, "manipulated, shaped, trained," forced to obey, to remain disciplined even as children who should have been more concerned with being happy than afraid or blind to our own pain (Foucault 136). My sister realized our plight far earlier than I did, which is why she became *lesser* in the eyes of our parents.

Foucault references the ranking system that arises in the wake of discipline and docility, recognizing that it is directly related to the overbearing head of the system and what they deem acceptable in the context of their expectations. My sister's obstinance was not deemed to be acceptable by our parents, resulting in her *lowering of status*, so to speak. The use of discipline within our household created a "hierarchical" system that ensured that my sister would be placed below everyone else, severely closing her off within our relatively small circle (Foucault 148). The damage rendered by the hierarchy implemented by our parents resulted in further ostracizing my sister from herself and us. She began to internalize the discipline assigned to us, even though she remained constantly against the established rules set by our parents regarding her body. Within the space of a few years, my sister had occupied a disciplined state without her ever even being completely aware of it, and she would remain in that state for many years to come, continually ignoring her pain because of the discipline instilled in her by our parents, telling her that her pain was nonexistent or a lie made up to gain a miniscule amount of attention—care—from them.



## She Cries Too Little

“No, stop complaining. You’re *fine!*” Our mother never wanted to believe that my sister could actually feel anything, always projecting on her a sense of aloofness that had never truly existed. The pain of my sister was constantly disregarded, even seen as fake—even by me, who knew what she felt on a daily basis. She seldom conveyed how she felt, and when my sister did, she was met with distrust and cruelty, hence why she so rarely made anything of her pain.

It’s odd reminiscing about the past and remembering its twists and turns, especially considering what I know now. My sister’s pain was called fake, even though I dare say she never actually faked any of her pain, unlike me. Of course, I felt pain on a regular basis, though knowing such a reality was known to our parents, I recognized that I could use my pain to my benefit. I knew which words to say and how to get away with what I desired most, which was to escape for a short while. Whenever my sister and I were sick as children, which we often were, we would stay with our paternal grandmother. I believe now that she knew I had been faking parts of my pain because I am now aware of how she treated my sister’s pain. I received a heaping pile of French toast for my troubles, while my sister was given the typical homestyle remedy: Sprite and a few tablets of antacids that never, ever did the trick of actually appeasing much inside of us.

I find it strange that our grandmother was so quick to accept my sister’s pain, even when it was invisible, yet she had such a difficult time understanding the sadness that would fester within my sister later into her teens. She saw one unimaginable pain and then ignored another.

The mental strain of the pain and having said pain ignored resulted in catastrophic damage that caused more than just physical harm. My sister battles bouts with depression that have sprung up over the years, typically in the wake of an especially life-altering event. Whenever she brought up her pain with our grandmother, she would be ignored or told, “Don’t worry so much, everyone goes through it; it’s natural to feel sad every once in a while, but that doesn’t mean it’s depression.” The authenticity of my sister’s pain was again questioned by someone who my sister had believed had her best interest in mind. This refusal of recognition stayed with my sister for many years, forcing her to keep everything bundled up inside, choosing to bury her pain alongside her tears in the deepest part of her being. Even when she tried to express her pain, every facet of communication was inadequate at best and further damaging at worst. She struggled for years, inching back into herself, leaving us all to continue formulating thoughts that poisoned us against her.

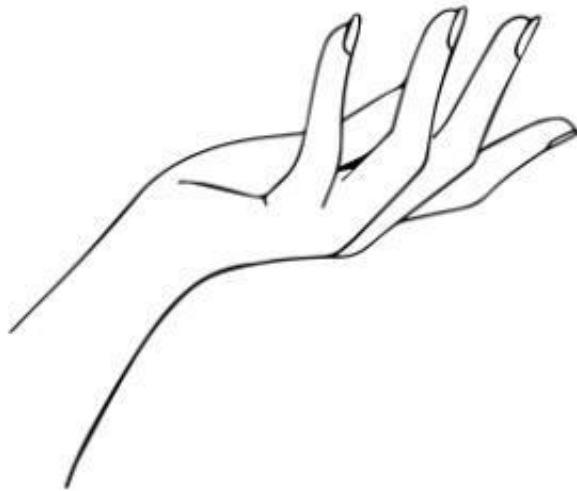
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The years of silence culminated in the deterioration of my sister’s health—both physical and mental. She went on in silence until she could no longer bear it, committing to something that would both damage and save her—something that I cannot speak of in this instance, for it pains me.

For the first time in our lives as sisters, I saw her pain culminating in a physically obvious sense, watching her as she spent hours huddled unceremoniously over a toilet, retching both body

and soul up and out. Her pain was brutally and completely visible long enough for all of us to recognize the similarities between the two of us, sisters with shared pain.

Pain is an indescribable thing that remains an enigma to me, even as I have and share it. How I describe it—how I *see* it—is entirely different in the mind of my sister, who has internalized it for years, feeling worthless because of it. Had I been more aware, had I been less self-involved—no, nothing would have changed because the pain would have still been subtle, even if it had been completely visible. The shared eating disorders, the anxiety, the nights spent huddled over a toilet hoping that something would come up so that we could return to our slumber, our lives were and continue to be controlled by our pain, and there is nothing we could have done differently to avoid it. Pain was our inevitability, regardless of shareability.





## Inexpressible Pain

Pain is nearly impossible to express in relatable terms. In the words of Elaine Scarry, who is one of the premium experts on the matter of expression, “Physical pain has no voice” (3). Even though my sister had the exact same pain as I did, I found it difficult to believe her simply because she didn’t describe it as I would have, using terms like “pressure” and “heavy” (Personal Interview). My sister’s pain was utterly foreign to me, *invisible* in its entirety. Scarry explores this perplexing phenomenon concerning the expression of pain, explaining it in as believable a way as conceivable possibly:

So, for the person in pain, so incontestably and unnegotiably present is it that "having pain" may come to be thought of as the most vibrant example of what it is to "have certainty, " while for the other person it is so elusive that "hearing about pain" may exist as the primary model of what it is "to have doubt." Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed (4).

Pain is unbelievable to all those who are on the exterior of the body, but to the person within, the pain is visceral, and the idea of someone not understanding is incredibly infuriating for them. In the end, it is “incredibly validating to have someone listen to your experiences” and believe you for all that you say, regardless of whether or not they understand the pain themselves (Leary). The physical, no matter of visible, becomes *invisible* as a result of the lack of communication regarding pain, leading to emotional distress within those—like my sister—who simply want to have their pain recognized and not framed as a lie intended as a ploy to garner attention.

Scarry places individuals like myself on the spot for their lack of awareness, questioning how it is “that one person can be in the presence of another person in pain and not know it to the point where [they inflict] it, and [go] on inflicting it?” (Scarry 12). I struggled for a long time to identify the pain I shared with my sister, and as a result, I contributed to the schism between the two of us. My own pain blinded me to her plight, swallowing my attention wholly, most of the time. Apparently, such behavior has been reported in others who, like me, are “Youth with invisible disabilities [who] often have trouble interpreting the intentions of others, are inattentive to others’ needs, and have problems with emotion regulation” (McLeod 19). *I* was inattentive to the needs of my sister, and due to that factor, I had fallen into what Scarry had described when it came to defining and expressing pain. In all fairness, “physical pain—unlike any other state of consciousness—has no referential content. It is not *of* or *for* anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language” (Scarry 5). I could not place my sister’s pain, and, in not being able to, I contributed to it. Without proper identification of her pain, my sister was forced to maintain her silence and subsequent independence. She became lonely, completely invisible, because of the inexpressibility of her pain.

## Her Independence and My Dependence

“I don’t want to live at home; I hate coming back. Mom and Dad always bitch at me about stuff, and I don’t want to hear it.” Every time I ask Taylor if she’d like to move back home, this is the answer I get. It’s the same answer I hear whenever I ask if she’d like to come on vacation with us or do things with us. I understand her anger and mistrust of our parents, for I share her anger at times. Our parents complain about her being in college and *not* being in college; they complain about her living situation and her expenses—which *she* pays. The list of the supposed wrongs that my sister has committed is lengthy, even though everything that our parents complain about is a reflection of their continual desire to control her; she hasn’t been controlled by them for a long time.

Her independent nature was developed by our parents, carefully cultivated over many years from unceasing chides and utterances of ‘*Don’t act like a baby.*’ My sister reached maturity far sooner than I did, yet our parents always said that *I* was more mature than her; I can attest that I was not, and that it still shows in who I am, particularly who I have been nurtured to become.

Where my sister was taught independence, I was taught dependence, to see our parents as my only access to safety and even autonomy. They nurtured my burgeoning anxieties about the world, never even letting me learn how to ride a bike—I’ve still never moved past training wheels. My development of dependency resulted in further validation of my pain, while my sister’s retreat into independence further ostracized her from her pain, leading her to even internalize grief against herself.

Internalized ableism has led my sister to ignore her pain on many occasions, even as the pain is meant to serve as a sign that she needs to take time to accommodate herself. I am on the other side of the spectrum, for there are times when I let the pain overwhelm me. The pain we share manifests itself at different intervals and intensities, yet it actualizes itself all the same, regardless of whether or not we ignore it or become entrenched in it. Our differences in handling our pain have led us further away from any semblance of relatability, yet we still persist in trying to understand one another.

“I know what you mean. They drive me crazy too.” I always do my best to validate the feelings of my sister. Perhaps by validating her feelings, I will eventually be able to help her validate her pain—recognize it and accommodate for it within herself.

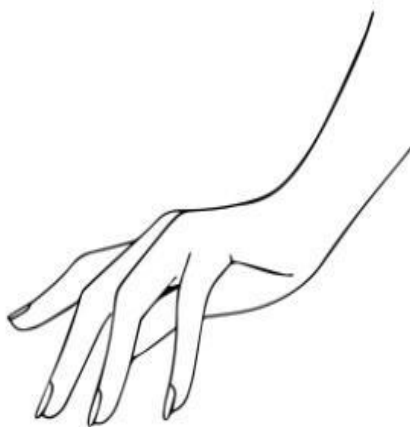
“I don’t know how you put up with them.” She thinks I *put up with them* because I do, but that doesn’t mean I want to. I was made to be docile, and I have abided by my conditioning, just as she has.

My sister and I are constantly at odds with one another, but not in an aggressive way, but in recognition of one another. I was blind to my sister’s pain, and now she is blind to mine. Our lack of awareness was spurred onward by a lack of communication between the two of us, beginning with my sister’s silence and hopefully ending with my own. Even such a simple validation can hide a storm beneath it, one that will one day rumble too close to the edge and be heard by all who are near it. Recognition begins softly but grows to be the visible portion of what has remained wholly invisible for as long as one can remember.

## Shamed and Enraged

People in our society already feel intense pressure to align themselves with normative concepts about their gender expression; adding on expectations for disabled people only builds on the pressure already there. It is incredibly stressful realizing that you don't fit the normalized standards of others, especially those that belong to people who we see as our primary care advocates, such as our parents. My sister personally shames herself for her pain on account of it 'othering' her when she has no desire to be ostracized or viewed as different. I myself now feel the same sort of shame, but on account of my loudness, having overshadowed her for years. Recognition for our bodies has been difficult to obtain, even from those within the medical field who should be able to help us. We have been forced to alter our approach to the medical system and to those who surround us, masking our pain in certain situations and exaggerating it in others—depending on who we are talking to.

Illness and disability are regularly alienated within our collective culture, and it stems from the perspectives held during the earlier part of history, especially in the Victorian era. Inability and illness within women, in particular, were framed as a dramatization, given “the diagnosis hysteria” (Werner 1037). Illness became a *woman's disease*, eventually even resulting in disability being coded as feminine in nature. Those who have a feminine gender expression or are forced to embody the feminine identity are then pressured into ignoring their pain or not communicating it to others simply because to be feminine—even when it was forced upon you—was to be obstinate or against normativity. Discussing pain becomes a “taboo” then, viewed “as a private and forbidden subject, something rather negative that becomes whining and complaining,” villainizing the feminine body, mine and my sister's bodies (Werner 1042).



## Things Will Never Be The Same

Pain cannot be ignored for long. Eventually, everything hidden will come to the surface, seen for what it truly is; real, not faked, not overdramatized, but *real*. Pain itself may be difficult to express, but it is vital that it *is* expressed; however little it might be. Silence results in nothing, merely the continuation of something which inevitably causes further damage and further pain. The damage done to my sister and I can never be healed. We will always deal with late nights next to a toilet, gobbling away at toast and antacids, or trying in vain to explore everything we can do to end the harm done to our bodies. The only thing we can rely on at this point is our shared recognition of the pain we feel as sisters.

We have a shared pain that has existed ever since we first drew breath in this world, and it is likely to persist well into the future. What we now know of each other has informed us to be gentle with ourselves and one another. We still struggle with addressing our invisibility with one another, and there are still hidden portions of our endured harm that remain to be unearthed with time.

My sister still deals with feeling less due to her pain, but she is working towards accepting herself, regardless of what has been disciplined into her. I have done whatever I can to accommodate my sister, and I continue to work toward validating her pain on a physical, mental, and emotional level. She also works to help me throw off my dependence and fear of the world, encouraging me to do things and go places regardless of the terror that shoots through me each time I do so. We nurture each other because no one else seems to want to do so, and it is through collaboration that we will find our way through this world as people who live with disabilities; *live with*, not hindered by.

Pain cannot be truly endured in silence. Expressing it provides a form of personal freedom that could not exist without voicing the pain. Even though pain is indescribable, it must *still* be described, no matter how difficult or fleeting it may be. My sister's pain went unnoticed and, subsequently, untreated for as long as she remained quiet about it. Even now, she has trouble expressing herself, but I do all I can to encourage her to combat the internalized fear of being called a fraud. Pain is a genuine thing that exists, regardless of whether it is visible or invisible, and all pain deserves to be recognized and respected; everyone has a right to be heard.

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Scarry understands pain, and now, because of her, I am able to glimpse my sister's pain in its entirety for perhaps the first time in my life; now, I understand *why* I never recognized her pain. I now know:

Physical pain has no voice, but when it at last finds a voice, it begins to tell a story, and the story that it tells is about the inseparability of these three subjects, their embeddedness in one another (Scarry 3).

I know her pain like the back of my hand, like the corners of my mind; I know her story because it is subtly my own. Her silence has rubbed off on me in the past few years, and as a result, I began to alienate my own pain, ignoring it for a long time. Unlike my sister, though, I have grown to

recognize the hurt, even accepting it as a reality that I must deal with, not with tears, but with communication and management. My sister continues to ignore her pain, relying on things that continue to hurt her, inflaming the walls within her. I don't want her to suffer this pain, and I hope dearly to convince her that she does not deserve any of it. Her silence and, eventually, my own, is a result of our parents, who disciplined us into docility within their household, though I cannot genuinely say that their intentions were malicious, as they—like us—were a product of their environment.

Foucault mentions that there are “four types” of disciplines that eventually develop the body into a state of docility:

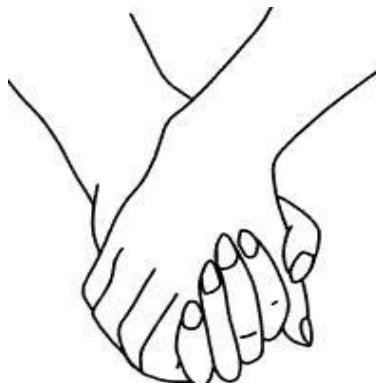
To sum up, it might be said that discipline creates out of the bodies it controls four types of individuality, or rather an individuality that is endowed with four characteristics: it is cellular (by the play of spatial distribution), it is organic (by the coding of activities), it is genetic (by the accumulation of time), it is combinatory (by the composition of forces) (167).

The bodies we have are defined by our environment and our discipline, and we all have been influenced by some means of influence, even if we may not have been aware of them. My sister and I were placed within a specific hierarchy, resulting in me being ranked above her due to my willingness to become docile; as such, I received more benefits—care—from our parents during our childhood, though such benefits have reduced me to dependency; we have accumulated our docility over time, though my sister has broken with the expectations to become independent from the discipline instilled against our bodies by our parents; everything we've endured—even what our parents endured—has culminated in who we have become and has informed our own manner of discipline as applied to others. Our parents grew up in households where invisible disabilities were staunchly refuted; mental illness was especially scrutinized. It is no wonder that our parents would grow to discipline us as they had been, for their environments had shaped them into who they would become: just as dismissive as their parents had been of them and their own differences. I don't argue in their favor in order to negate any of the blame that rests at their feet; I only mean to recognize that they had been influenced to think as they do by outside sources. I don't believe that our parents were entirely conscious of what they did to my sister, but that doesn't excuse everything they put her through.

In the grand scheme of things, “people learn ableism from others, consciously or unconsciously,” resulting in the continued instigation of shame that has been forced onto people with disabilities (Villines). The ableism of our parents towards me was a form of “Benevolent ableism,” or the form of “ableism [that] views people with disabilities as weak, vulnerable, or in need of rescuing. This is patronizing and undermines the person's individuality and autonomy, reinforcing an unequal power dynamic” (Villines). My sister experienced an opposing sort of ableism known as “Ambivalent ableism,” which is a combination of “Benevolent ableism” and “Hostile ableism,” which is often characterized by “openly aggressive behaviors or policies, such as bullying, abuse, and violence” (Villines). I cannot, without a doubt, state that either of my parents went through any of the forms of ableism that were inflicted upon myself or my sister, but

I do know that my father experienced a much more obvious bout of ableism due to his Attention-Deficit Hyperactivity Disorder, which was passed down to my sister who had it for years before finally being diagnosed in her senior year of high school. Even with all the evidence showing that she had ADHD, our parents chose to ignore it because they didn't want to believe that she had anything different about her; the disability she shared with me overshadowed all of her other disabilities and was framed as false, causing our parents to believe that everything concerning her was false. It is arguably not so surprising that my sister's ADHD went undiagnosed for years, especially when we consider our dad, who didn't even believe that *he* had ADHD. His disability was labeled as laziness, and that label was passed from him to my sister. The point of the matter is that our parents ignored my sister because she reminded them of who they had been as children in her place. Their own internalized ableism forced them to attack my sister—their daughter—forming the rift that remains ever present even years after my sister became wholly independent; the judgment never goes away.

My sister has never once deserved to have her pain ignored or called fake, and it concerns me that she still deals with internalized ableism as a result of the conditioning of our parents. It took me years to get to where I am emotionally, yet there is still a great deal that I need to address before I feel safe and in control of my body, the latter of which I will never fully be able to obtain. My sister will similarly never be able to gain complete control over her pain, but I know, from personal experience, that we are capable of finding a modicum of comfort in managing our pain as well as discussing it. There is nothing so validating as communicating and listening to others as they describe their pain. Everyone deserves to have their pain recognized and actualized, especially since so many of us will eventually gain a disability in our lives. At this point, “15% of the global population” experiences life with a disability (Villines). That number might seem small, but that is just what has been documented. How many others go uncounted simply because they remain silent? Their voices matter just as much as those who *do* disclose their disability, and it is up to the rest of us—those who speak up or have no disability at all—to help those without a voice command the attention they deserve. We all have a right to be heard and seen. I hope I am able to help my sister realize one day that she doesn't have to be trapped in who she was disciplined to be and that things don't have to be the same as they have always been. Things can change; we only need to speak out in order to do so.



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