

## A Crippled Cassandra

By Kelley Shinn

In 1991, after a disfiguring brush with death, I was told it would be unlikely I would bear children. I remember the prognosis was that *if* I were able to conceive, it would be wholly overwhelming, if even possible, to bear the child. The doctor's reasoning did not seem illogical: I had survived meningococemia and sepsis, barely. Due to necrosis, my legs were slowly amputated just below the knees, my arms and thighs debrided and skin-grafted like a child might eat a fresh-baked loaf of bread, randomly plucking out cottony, yeasty billows. My organs were taxed after a month of close calls, and one call that actually came through, though it was hung up on after seventeen seconds of defibrillation and a subconscious alternative world decision, if you will. My kidneys threatened failure, my brain threatened to hemorrhage, a lung had collapsed, I had multiple severe infections, including vaginal, as the result of a litany of lifelines—tubes in my crotch, into the heart, down the throat, in arms—tubes that kept me alive, tenuously. I was hospitalized just under 100 days. I'd had well over a dozen surgeries. In all the strange ways that we define it, I was a miracle. I was sixteen years old. And that doctor wasn't completely wrong either: I've had three miscarriages, one of which was the loss of a twin. But I have given birth to three children, two who made it out of the delivery room alive and are still with me today.

I now balk at that prognosis, despite the appearance of truth in it, as I've born and am raising two healthy children. My daughter, Cecilia, will be driving imminently, and Silas is seven. There's no way for me to express the smug gratification that occurs when you beat enormous odds. Mind you, I wasn't trying to make babies to prove a doctor wrong—it's just a pleasant late afterthought in the game. It's akin to the juvenile belief that you can go out into the ocean as far as you want and not drown. When you finally leave your comfort zone, the ocean smacks you with what is a small wave for that deep in, and you find yourself clamoring for breath, nervous about your wager, and you turn yourself around, looking dizzily for the shore, grateful when you get back to your beer, warm or not, in the sand. As you get older, you weigh your strength on any given day as to whether you even go into the water or not. On a rough day, you sit on the shore at the farthest point, where the ebb begins. If you have them, your toes get wet. You look out at that ocean, and you say—*Ocean, you are not only so beautiful that centuries of poets have given up their firstborns trying to describe you aptly, but more importantly, I respect you. I do not think you are mine for the taking.* So on the one hand, I congratulate my childish self for outsmarting a doctor, and on the other I pray fervently for the protection of the children who I am so grateful to have borne.

When the doctor shared these thoughts with me at the age of seventeen, I was indifferent. Aside from a month-long notion at fifteen, where I dreamt of adopting a child from every country and raising them all in some temperate, aesthetically beautiful bunker as a juvenile world peace project, I never dreamt of having children. Now, I only need sit in on my son's first grade class for ten minutes to know on a profound level that many dreams are better not realized. But what I also did not realize at seventeen was that there was no logical

medical reason for that doctor to tell me what he did. There was no damage to my reproductive organs or any other organs for that matter, which never did completely heal. At the time of that doctor's comment, I had prosthetic legs and a roadmap of scars, an emotional road to hoe but nothing that could definitively point to an inability to bear children. And though I can't presume to know why he shared those words with me, I can't help but wonder if he was discouraging me simply because I had become a crippled woman.

Though it might make us squeamish to think it so, throughout history, society has actively discouraged disabled women from having children. Perhaps I am inclined to state that mildly because of the horrific implications the truth has brought to women like myself in both the past and present. The forced sterilization of women who are deemed disabled still occurs on a global level. When Hitler's forced sterilization program began to draw harsh criticism, he quietly transferred the facility to a concentration camp and was responsible for the murder of nearly a quarter million disabled people, primarily women. These heinous acts find their origin in the practice of eugenics, an applied science originally pioneered by the United States and Germany that sought to rid society of defective gene pools. America was the first world leader in forced sterilization. During the mid-20<sup>th</sup> century, until the 1970's, America removed the choice of motherhood without consent or knowledge from approximately 65,000 women. Nearly half of those procedures took place in California alone. The majority of those women were disabled or institutionalized, but large numbers of those women were not; instead they were deemed a threat to society on the basis of being morally deficient simply because they were African-American or Native-American, and poor. The International Criminal Court considers forced sterilization a crime against humanity, yet it is still a hotly debated issue from Peru to Japan. There isn't a single continent on earth that has not practiced these crimes against women.

The Americans with Disabilities Act broadly defines disabled as anyone having a mental or physical impairment that substantially limits one or more major life activities. Under this vague bureaucratic terminology, I have asked myself if I truly qualify as disabled. How does one define a major life activity? I cannot run, though running was an essential part of my youth as a promising track and cross-country runner, but even if I wanted to, I have a middle-aged skeleton that would surely protest. Can running even be considered a major life activity outside of mass anarchy and wartime? I can't sit Indian-style, shaving seems like folly, and I sometimes wish I could pull off a short skirt. Major life activities? Not so much. I can no longer feel the warm sand under my feet, which may be the only aspect of my loss that still enables me to consider it a loss. When my children were small, I worried that I may not be able to react quickly enough in moments of danger, but how does that concern differ from any other mother, legged or not?

I am a crippled mother, though I don't see myself that way. The state of being crippled and a mother do not intersect directly in my experience. Indeed, they tend to run parallel, reverberating off each other at times but never crossing the lines. Nancy Mairs writes in her well-regarded essay, "On Being A Cripple," that crippled people are only accepted as complete by society when they are superhuman. They must not only function at a normal level, but they must exceed it. "A grumpy cripple," she writes, "is not playing by the rules." When my daughter was born, I understood these guidelines on a subconscious level. When your bodily image is shattered and you nearly lose your life, fear often takes the backseat for a while. You have nothing to lose, after all. When my daughter was young that fearlessness was still inside of me. I was young, too. When she was two-years-old, I drove her across the United States and back, competed in off-road driving competitions with her,

and when that wasn't enough, I picked her and her blanket up and dragged her a half way around the world to work with landmine survivors in Bosnia-Herzegovina. I unwittingly spent the night with her in a whorehouse in Czechoslovakia and nearly killed both of us twice—once while off-roading in the Alps near Innsbruck, Austria and later while swimming to an island in the Mediterranean Sea off the coast of southern Greece. All three of those experiences are some of my most cherished memories with Cecilia. Throughout those experiences, my daughter never lost confidence in me. She never even expressed a sense of danger. When she was young, she thought I could do anything. There is most likely some truth in the fact that my being crippled contributed to those situations. They all derived from a lack of fear and an urge to overcome boundaries, to live this life, which I nearly lost, to its absolute fullest. But I haven't yet met any able-bodied parents that can't recall a moment of vivid fear in which they thought their child was in danger, and they felt there was something they could have done differently.

There is precedent for my drive to be a crippled hero in the Hephaestus archetype. One version of the myth tells us that when Hera gave birth to Hephaestus, she was so disturbed by his clubfoot that she threw him off of Mt. Olympus. Hephaestus eventually returned to Olympus, the only god banished to ever return, and became revered for his art—he made beautiful jewelry, weapons, Apollo's chariot. He was an intellectual and a loner, who only overcame his wounds by healing others with his gifts. And he married that sensuous beauty, Aphrodite. Hephaestus and Aphrodite as one is an alluring juxtaposition, but for a woman in my position to aspire to be the archetype of such a union is socially unacceptable, because the crippled have been historically regarded as asexual. The theory is that the crippled are dependent and therefore, childlike, and any propensity for sexuality is deemed overbearing, even perverse. I have never conceived of such boundaries. In fact, it seems ludicrous to me that it would be just short of blasphemy for me to state that I am a crippled woman who thoroughly enjoys the gift of making love. I also enjoy self-imposed bouts in the nunnery so I can focus on my art. Hephaestus and Aphrodite, indeed.

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Perhaps, because life threw me a knuckleball when I was young, and the course of it made it easy to defy socially imposed standards, I continued to do so without forethought. Following intuition is the way I survived the emotional loss that came after the physical one, and intuition is often unorthodox. I grieved hard and terribly. I attempted to self-destruct right up until the moment when I nearly hit bottom, and then I simply decided I'd rather learn to live at peace with the body I'd been given. On that road, I met two men with whom I bore children and declined marriage proposals from both of them, though I still love them both. While those rejections were for a myriad of different, temporal reasons, it seems to me now, in retrospect, I knew I had a journey ahead of me that could not at that time include them in a conventional sense, and, wrong or not, I felt that is what they both wanted. Those decisions were a far cry from the choices that I didn't even think I had as a girl who lost her legs at sixteen and was terrified that a man would never love her in the light of day. And to be fair and honest, I perhaps also questioned whether the fathers of my children could love me in the light of all my days. This sentiment also appears to be universal, legged or not. Whatever the case, those decisions represented the rational, sensitive mind of a free will, and I do not regret them. However, again, from the

conventional view, I am not the woman you'd want to bring home to mother—a no-legged nomad with two illegitimate children from two different fathers. That said, our home life, our nest, thrives and pulses with love, and visits from beloved fathers—we're a good and honest trio.

Out of the lack of convention in my life thus far, arises the archetype of Cassandra. Cassandra, if you recall, was the daughter of Priam and Hecuba, the king and queen of Troy. As a child, she and her brother, Helenus, were left overnight in the temple of Apollo, the complex god of light and sun, associated with medicine and healing, truth and prophecy, music and poetry, and the patron defender of flocks and herds. When their parents returned for them the next morning, they found the children entwined by serpents who were licking their ears clean. This was a gift from Apollo. The brother and sister were given the gift of prophecy. Cassandra's beauty was compared to Helen's, and she had many suitors, including Apollo himself. As a young woman, she revisited the temple, and Apollo attempted to force himself upon her, yet she rebuked him. So incensed he was, that he cursed the gift he gave her. She would still maintain her ability as a seer, but anyone who heard her would think her mad. She would not be believed. And so it was, when she foretold the fall of Troy, when she warned of the Trojan horse, she was not believed. Indeed, she was persecuted and locked away for a time, and after the fall of Troy, she was raped by Ajax in the temple of Athena. All the while, men were still drawn to her. After the war, King Agamemnon took her as a concubine back to Mycenae where she bore him twin sons. Later, Clytemenestra, the estranged wife of Agamemnon, and her lover, Aegisthus, murdered Agamemnon, Cassandra, and their sons. Many believe the famous archaeologist, Heinrich Schliemann, uncovered Cassandra's tomb in the late 1800s, where her bones lay with her sons beside her.

I do not feel entirely comfortable with drawing comparisons between Cassandra and myself, and that discomfort lies, as usual, in some plain truth. The German literary critic, novelist and essayist Christa Wolf wrote in her novel, *Kassandra*, "Wir können, was wir sehen, noch nicht glauben. Was wir schon glauben, nicht aussprechen." *We can, what we see, not yet believe. What we already believe, we cannot express.* Wolf uses the story of Cassandra as a metaphor for her personal experience as a censored female writer living in East Germany during the Cold War. The innovative British psychoanalyst Melanie Klein portrays Cassandra as moral conscience driven by a cruel superego represented by Apollo in the myth in her book *Envy and Gratitude and Other Works, 1946-1963*. Cassandra's rants provoke in others "a refusal to believe what at the same time they know to be true and expresses the universal tendency toward denial, [with] denial being a potent defense against persecutory anxiety and guilt."

I empathize with that "universal tendency toward denial." Indeed, in the years following my slow amputations, I could not utter the truth aloud. I would not allow a lover to touch me below the thighs, I lived with people whom I never told, and would disappear in the night if they confronted me. For years, I could not say the word "stump." That denial of truth nearly killed me a second time. Every day now, I wake and must slip on my prosthetics and think of them as a hundred different metaphors, all leaning toward hard truth. I, like Christa Wolf, am a writer, who writes about sensitive, inflammatory themes. I, as Melanie Klein suggests, poke incessantly at the human conscience, and most insistently, at my own. Those two women initially drew criticism for their outspoken views as women. I can't help but feel I up the game as a cripple and a mother whose actions have been oft criticized, or in more polite company, have caused eyes to roll. It stuns me still—as the

closer I feel to truth, the closer I feel to all the gods. Indeed, in so many conventional realms, on any Fox news program, one could dismiss me as another Cassandra.

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Given the previously mentioned definition, I am not disabled. I have travelled much of the globe, including war zones; I have been mountain climbing, kayaking, dancing, and I've breastfed an infant while operating a tractor. But let us maintain sobriety for a moment. According to a 2012 report from the United Nations High Commissioner for Human Rights presented at the United Nations General Assembly, "The Convention on the Rights of Persons with Disabilities recognizes that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, and expresses concern about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination." Dick Sosbey, director of the John Dossetor Medical Centre for Ethics in Alberta, Canada, states that nearly eighty percent of women with disabilities will be the victims of sexual violence at some point in their lives. Other statistics suggest that one quarter of disabled mothers are likely to lose custody of their children. Women with disabilities have a more difficult time finding adequate housing and gainful employment—the list goes on as long as human cruelty. And the fact that I have experienced all of those statistical hardships on some level unnerves me. It makes it all too easy for me to fit into this category, to be defined. It takes me to a sorrowful place, one that is raw and legless and vulnerable. It lays me bare before the death wall.

The line is exquisitely fine in the bureaucratic, psychological world of category making. When the United Nations creates a program to help end violence against disabled women, they must also define them. This definition, by its very nature, creates a subgroup, and this is the realm where human devaluation begins. Ervin Staub, Professor Emeritus of Psychology at the University of Massachusetts Amherst and author of *Overcoming Evil: Genocide, Violent Conflict and Terrorism* once wrote that "[When] devaluation becomes a part of a culture, its literature, art and media, and is perpetuated in social institutions, it becomes highly resistant to change. Even when its public expression is quiescent, it remains part of the deep structure of the culture, and can re-emerge, for example, when a scapegoat or ideological enemy is needed." This is as true for disabled women as it is for African-Americans, for homosexuals, for white men, for any among us who bear any distinctive mark of identity. These categories are futile, and farcical, and yet what order would we have without them? It is at moments like these—moments where hope seems awash—when I find solace in the words of the Nobel Prize winning author and philosopher, Albert Camus. In *The Myth of Sisyphus*, he reflects so poignantly on what seems to be the absurdity of life. Sisyphus, if you recall, is punished for his perceived levity against the gods, and for eternity must push a stone up a mountain, only to have it roll down again. But Camus revolts against the perception of futility; indeed, he ends the famous essay by saying that "The struggle itself towards the heights is enough to fill a man's heart. One must imagine Sisyphus happy."

I am that happy Sisyphus, even in my own imposed categories—as a writer, as a crippled woman, and as a mother. My children are learning to understand me and I

them. They are very different beings, both in gender and in temperaments. Cecilia has always accepted my physical frailty as anything but frailty. Once, I worried my children might be ashamed to have a crippled mother, but I could not dwell on that—there were too many dishes and clothes to wash, diapers to change, stones to roll. When Cecilia was nearly three, she sat on the floor playing with blocks. Her aunt was sitting on the couch next to her, and I will never forget when Cecilia looked up at her and said, “Aunt Claudia, take your legs off and get on the floor with me.” Claudia looked at her in disbelief, and explained that her legs could not come off, to which Cecilia replied, “Oh, Aunt Claudia, all mama’s legs come off.” Cecilia is now a teenager who wears a t-shirt with the words: *Gandhi says relax* on the front while she shows me a collage of the Holocaust she made, and explains how apathy and indifference are the causes of atrocity.

Silas is still a small boy and is learning to come to terms with the fact his mother does not always fit his masculine drive to be superior. Once, in Toronto, a man in a wheelchair that was pulled by two huskies came up next to us at a red light. I looked over at the man with great admiration and found myself very discomfited when Silas exclaimed, “Oh, that’s gross.” The man had amputations almost identical to my own, and his bare stumps were hanging over the edge of the chair.

“What’s so gross, Silas?” I asked.

“His legs, Mama.”

“Silas,” I half-pleaded, “do you think your mother is gross? He is cut the same as I am, yet you crawl into bed with me at times, and into the shower...”

“But you wear your fake legs, Mama.”

“Not in the bed, not in the shower.” His words had stung, and he could not yet process his thoughts. The conversation ended there.

Weeks later, I went to pick him up at school. To my knowledge, none of his friends knew of my prosthetics, but that day an outspoken boy shouted from the line, “Silas’ mom, why do you have fake legs?”

I looked at Silas, afraid to shame him or to betray his still-fearful heart.

“It’s okay, Mama,” he said. “I told him on the playground.”

We all went outside and I took a leg off and let the kids pass it around. They swarmed around me, every one of them wanting to hold the filthy trophy. Silas was proud of his token, crippled Mama that day. Maybe it is because I helped set him apart with something unique at a time when he struggles with the distinction between conformity and identity, or maybe he’d just finally begun to process that nothing is so gross after all.

That same week, he hopped in the shower with me. I was upright on my knees, legs half-akimbo, elbows raised as I washed my hair. Silas pulled the curtain back, and said “Oh, Mama, you look just like Patrick!”

“Patrick,” I asked?

“Patrick the starfish, from the Sponge Bob cartoon,” he replied. Shampoo ran into my mouth as we laughed together. His raw honesty was hilarious—life’s absurdities often are—but the Patrick character, while consistently blissful, isn’t so bright.

“I hope it’s only my image and shape that reminds you of Patrick and not anything else,” I said to my young son.

“Oh, Mama,” he replied, and walked across the bathtub, wrapping his arms around my waist and burying his face into my chest. I sat down, and he straddled my waist, his small, callused feet rubbing together against my tailbone, and I held him in silence under the shower until the water went cold.

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Up until seven months ago, my children and I lived on an 85-acre farm in the Appalachian Mountains in Virginia. We lived there for nearly a decade. Silas was born into that mountain. We could see only one home from where we lived, and daily, we communed with the animals of the mountain—the deer, the bears, the groundhogs, the turkeys, the snakes, the woodpeckers, and sometimes, the coyotes. My children often witnessed the brutality of nature, the vultures that would come to clean it up.

We had a garden every year but our last one. I am not a skilled gardener, but I understand the basic concept: seed in ground, water and sun, food. When Silas was tiny, we’d give him a bucket of water and a wee shovel and he’d make mud while Cecilia and I tilled the earth, made bamboo structures, webs of twine, raised beds and rows. Every year, I’d attempt to read the Farmer’s Almanac and other gardening books, trying to hone the skill. Nothing ever really stuck, or seemed to work, and as it was, I felt rather accomplished when I tricked Silas out of diapers by encouraging him to pee around the periphery of the garden to keep the deer away. But one year, I’d read that you could yield a stronger crop if you thinned the shoots when they came up. I sat there, legless in the dirt, as it was easiest for me to plant seeds that way—something I learned by observation from a landmine survivor in Bosnia-Herzegovina—and I explained to Cecilia how to pick the frail shoots out, how to space them. She looked up at me with an expression of sorrow in her face, and said, “But, Mama, that seems so cruel.” My daughter called me out. I leaned back on my hands, wiped my forehead, and realized I had become Hitler in the garden.

“What will you have us do then, Miss Celie?” I asked.

“Mama, I say let them grow how they will.”

And so we did. And our garden that year was the most lush, green, fruitful entanglement we ever saw. And the small plants, the ones that didn’t make it through the season, might have given off only one fruit—but it was divinely succulent. Late into the fall, we were still untangling the roots, uncovering watermelons, pumpkins, peppers and eggplant. The herbs never seemed to end. That season, Silas was never without a strand of basil, thyme or oregano in his mouth. And when it was over—when the frost was palpable in the air—we

yanked and shoveled all day long, throwing all of the coarse and woody vines into a pile, which later burnt throughout the night.

Camus is right—nature, at its very best, is absurd and chaotic. It takes the legs off of some women who refuse to quit walking. When the body begins to be chiseled away, the true nature of the spirit becomes more acute. It's akin to the blind man's keen sense of smell. I can speak firsthand about the loss of body and the uncanny sense of intuition that has come to rest in the place of that loss. From the very beginning, it seems my life has been preparing me to be a voice for the suffering. I have held the hands of victims of war in Bosnia-Herzegovina, had many a shirt soaked in the tears of the dying and injured, and have led the bodies of several loved ones back into the earth—a tiny son among them. Sometimes, it does all seem futile and hopeless. Grief is a brilliant, yet brutal teacher. But I agree with Camus: I imagine Sisyphus happy. I choose to revolt. I choose to gaze upon the dead and to wash and oil the outer shells of those I have loved. I choose to write the stories of humanity with as much dignity as I can muster. The fruit of even the shortest life is succulent and sometimes more so.

The only defense we have against the heavy burden of the stone is the love of pushing it. In the language of boundaries, the only commonality between my life as a crippled woman and my life as a mother is this: the love I have for my children is defined by the same immense fragility and vulnerability I have as a legless woman in an all too often cruel world. If I were to lose them, I would be crippled all over again. They hold me up in the greatest of strides.

I remember the years they both suckled at my breasts, the high-pitched, eager swallows coming from their bodies. I do not offer my children shiny packages laden with false promises—I offer them this body, what is missing from it, so that they can learn that ultimate love transcends the physical, so that they can learn to relish the body—theirs' and others'—while they can, in any form. If I desire to give them anything, it is compassion in its old, weathered box—the ability to revolt against the futility and hopelessness, to live as brightly through the night as that garden fire at the end of the harvest. I think these things and try to convey them without overwhelming my children as we row kayaks out into the lake. Once we reach the island, we laugh as the ducks fight for the scraps of food we throw to them, we bite into our apples as two swans float by, we shudder in awe as the great blue heron that we did not see before, takes flight.

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