

# Emily's Story

and the Expression of Pain

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Emily Johnson-Pars was a painter. She had other titles, mostly mom and Line Manager at GOMACO manufacturing, but her deepest self wanted to be known as a painter. Not that she wanted to be famous, to be clear. She felt most herself when she was able to slip away for an hour or two, and put a brush to cheap canvas. There her mind could run free, explore a world much outside her own, and capture something as close as her meager skills would let her to what she could imagine. She would often picture herself on a late afternoon in Paris, her brush strokes melting into the warm hum of the city street below. The air would smell of late summer, the trees giving off their vibrant earthy aroma as the retiring sun doused the Parisian rooftops in shades of gold. She could just make out the Eiffel tower if she moved her easel to the left. Emily had tried to recreate this image on her canvas many times, but her brush never seemed to convey the warmth she felt in her mind's eye. She longed to go to Paris, to see if she could find a tiny semblance of the afternoon she imagined. That would never happen, she knew, but it was a nice escape on occasion from the razor blades in her stomach and life in Ida Grove.

Ida Grove was a small town in Western Iowa, home to "The Worldwide Leader in Concrete Paving Technology" GOMACO Corporation. Also, the town had three filling stations, a McDonalds, and a newly remodeled Wal-Mart. Ida Grove could be described as a rather sleepy town, but Emily had spent all her life here. She grew up the daughter of a custodian at the local high school; her mother was a cook at diner on Main Street. She went to community college nearby for a year before taking a job on the line at GOMACO. As is common in construction manufacturing, the corporation's financial stability was closely tied to the success of the

economy at large. Every time the rumors of financial instability started, Emily would worry if she would keep her job. Sure, she had worked there for twenty-something years, starting on the line and working her way to line manager, but her boss was an ambitious young man and was always looking to cut costs for the company. As a middle-aged woman with a family, she knew her benefits were a prime target for budget cuts. When the razor blades started limiting her abilities at work she knew it was a matter of time before she was asked to move on.

Her family consisted of her daughter Amelia, her youngest Jacob, and her second husband Jeff. When the razor blades started Amelia was a quiet and inquisitive twelve-year-old, with an unyielding affection for sea turtles. She wanted to be a marine biologist and travel the oceans studying sea turtles. Emily often kidded Amelia that she would have to learn to swim before she could ever go to the ocean. Jacob was a rambunctious five-year-old and was the light in Emily's life. Whenever she had a hard day at work it felt comforting to come home and listen to the shenanigans Jacob had gotten into that day. Emily and Jeff had married a year before having Jacob, she had divorced Amelia's dad years before. If you asked her why, she would say they had a dispute and she had asked him to leave. He had promptly moved out of state when the divorce was finalized. In reality, he had hit her during an argument and she had threatened to contact the police if he stayed in town. Her father had hit her occasionally as well, but she gained a lot of confidence in herself when she started working on the line. As soon as her first-husband hit her she knew she wasn't going to withstand abuse any longer. Those incidents left her with scars, however. At times she had crippling anxiety that the world would

take advantage of her, she worked hard at her job to make sure this never happened. Her job was a source of great pride to her, and the pain jeopardized her standing with the company.

The pain started a couple of years after she had her son. She would have initially described it as a heaviness in her pelvis. Over several years this progressed to outright pain, especially with movement. It was part of the reason she was promoted to manager, her old boss knew she was dealing with a lot of pain while assembling parts on the line. The OBGyn that delivered her children convinced her she needed to have a hysterectomy due to uterine fibroids. So she did. She had reservations about having a procedure, she had known other women who had hysterectomies and the recovery seemed very long. She could vaguely remember going under the knife as a child during an episode of appendicitis. All she could remember was the overwhelming anxiety she felt then before she drifted off to sleep, the thought of being completely powerless and unaware of what was happening scared her. Nevertheless, she agreed to do the procedure. The pain never really went away after surgery, but it was different now. It waxed and waned, but at its worst she would tell her husband it was like hot razor blades were shifting around her abdomen. It made her gasp and reach for something nearby when she couldn't distract herself from it. When it wasn't so severe to feel like razor blades, it was constantly present as a dull feeling of discomfort that she could never quite push down to her subconscious. It was difficult for her to describe to people, her mind also pictured it as sharp rocks in her stomach sometimes. It was never enough to make her cry but always sharp enough to bring the pain to the forefront of her consciousness when she tried to distract herself. She could tell that Jeff thought she was being dramatic when this first began,

but as the months and years wore on, he quietly accepted that this was the new normal of their relationship. She would spend much of her free time in bed, she preferred to be alone. Their relationship continued to distance through the years, however they always made an effort to convey their love for the children. He could not understand how someone could constantly be in the pain she described, and she could not find the words to make him understand. She could not find the words to make anyone understand. Ever since she was a little girl, when her father had belted her for spilling a bowl of cereal, she had a hard time putting her emotions into words she could communicate to others. It was better not to speak about emotions. Painting was her outlet of choice for expression. There was something strong about the visuals she created that spoke to her more than words. She tried painting her pain sometimes, just to express the agony she felt daily. It usually came out as dark, looming and vague figures in the night. Perhaps like a cliff of sharp foreboding rocks that she was to climb, but never reach the top.

The doctor was a short, stout man with trim graying hair fitting for a doctor. He was the primary physician for Ida Grove and the surrounding area. As such he was a busy man, and Emily always felt rushed to explain what she was experiencing when she went to see him. Not that she ever knew the words to describe what was happening to her. The first time she saw the doctor about her pain, he suggested proceeding with a colonoscopy to look for a gastrointestinal issue. He would do the procedure himself. Emily was certain that her pain wasn't from an irritable bowel or some kind of intestinal disease, but at his urging she agreed to the procedure. Nothing abnormal was seen. Next, she got a CT scan of her abdomen. Again

nothing was remarkable. She was referred to a general surgeon, who performed something called a lysis of adhesions. They opened her abdomen and cut away some of the inflammatory tissue that had built after the hysterectomy. It did not help however. Emily thought it might have made things worse. She pleaded with the doctor that they would do no more operations. After this the doctor tried to control her pain using a medication called Tramadol. Emily was thankful because it did take the edge off of her pain when it was at its worst. One night she painted herself in a small box, trapped and with little room to breathe. The medication allowed her to push the sides of the box out just enough to breathe comfortably. This worked for a few months. However, she began to need to more and more of the medication in order to prevent “rushes” of pain when she didn’t have the medication in her system. After almost a year of steadily increasing dosing and frequency, the doctor told her they would need to try something else. He started asking her about her sleep. It had been poor for many years, of course because of the pain she told him. It was worse at night with her mind unoccupied. But even before the pain she had slept poorly, anxious thoughts racing through her mind. He asked her about her appetite and some other things as well. She thought the questions were odd but found herself saying yes to most of them. The doctor left the room. She wondered what the doctor does when he leaves the room: talk to nurses? Jot down some notes? He returned much more quickly than she expected and started talking rapidly about depression and how the pain she was feeling may be caused in part by her depression. She left the doctor’s office with a prescription for an antidepressant and instructions to return in six weeks or go to the ER if she was “feeling suicidal.” She took the medicine, one time per day for six weeks. For the first several weeks she felt nothing. It’s as if she was taking a sugar pill. By the time she returned to

the doctor, she still felt nothing. She told him as much and he suggested that maybe with another month of treatment the medication would start to improve her mood. That made her want to scream. "If I could just have a day without pain maybe, just maybe, I wouldn't be such a miserable sack of you-know-what all the time doctor," she said under trembling lips. She went to bed as soon as she got home and cried. She cried for a long time. Her stomach hurt tremendously. She imagined stabbing herself in the stomach, killing the pain, and the relief that it would bring. Being angry seemed to help distract her from the pain. In what seemed like just a moment later, Jacob was home from school and wanted a snack. She rose, took a tramadol, and went about the rest of the day with the raging helplessness pushed deep into the fibers of her soul so as to snuff it out.

The Dilaudid was suggested by the doctor once they had "maxed out" on the amount of tramadol she could take. Emily had recently quit her job, she could barely face the workday knowing those razor blades would be dancing around her abdomen. She knew her boss was not sorry to see her go; she had hardly been of much use at the plant, unable to move at much more than a tender shuffle. They switched from the Tramadol to Dilaudid. It was a stronger medication the doctor explained. She initially started taking two pills per day. Eventually those minutes before her next dose began to be some of the worst times of her life. She began to crave the feeling she would get after taking a dose. It was like everything was reduced, dulled to a far-away roar. She could hear the pain but it couldn't hurt her there. As the medication wore off the roar would come creeping toward her, like a train coming from a distance. And like a train, the pain was unstoppable when it came for her. She knew she was addicted to the

medication and she didn't much care, frankly. It had made life somewhat normal. She had a routine now. She could tell she was in a fog for most of the day, and she overheard her daughter commenting on it to Jeff, that mom had no emotion and seemed sleepy all the time. Emily knew that she became dull when she was on the medication, but it was so much better than laying in bed and fighting mental battles with the pain every minute. Eventually, this became the new normal; her personality became lifeless. While she was able to perform the functions required of her as a mother, her relationships with family and friends deteriorated to mere formalities of conversation. She could become furious at the drop of a hat. There was no life in her life; the longing for her bed did not change despite the fact she had a routine now.

The specialist was a doctor in Sioux Falls that she was referred to when she started pressing for more Dilaudid. The doctor told her that this was someone who specialized in pain and may suggest some new ideas, such as injections or new medications. Emily was skeptical that anything new was going to help her. They had tried so much already. She finally had rhythm to her life, and while her new normal was not ideal it did at least keep her from battling the pain constantly. She knew she could say no if she was not interested. However, on the drive to Sioux Falls and reflecting on her last few years of misery, she couldn't help but notice she had not said no to anything the doctors had suggested. She was a helpless vessel, subject to their experimentation and medication. She resolved to say no this time if procedures were brought up. When the specialist walked in she introduced herself and began to explain what the pain clinic could provide to Emily. Then, she asked Emily to tell her story. It took about 40 minutes. Emily started with her fibroids, then the hysterectomy, how the pain didn't get better



after surgery, then all of the things that they tried, the procedures, and finally the Dilaudid. She teared up towards the end thinking about what life had become. The specialist sat quiet for a moment, thanked Emily for sharing, and she said, "This may be surprising, but I know multiple patients with something similar to what you are experiencing." Emily always knew she could not have been the only one experiencing this, but it sure felt like it. She told the specialist this. The Specialist nodded and told her that there was a support group that meets in Sioux Falls of patients with similar problems, and that she should check out the Facebook page. The specialist told Emily she was diagnosing her with something called Centrally Mediated Abdominal Pain Syndrome. She explained that while there were obvious things that provoked the pain, like the hysterectomy, her brain was abnormally amplifying signals coming from her intestines and perceiving these signals as pain. The problem was actually in her brain. So, the specialist wanted to try some techniques to retrain Emily's brain how to perceive these signals. Emily was surprised by this. She thought there would be more pills and procedures, and she reminded herself of her promise in the car to say no. However, these new concept of her pain left her grasping for words to say. She sat there for a moment. "So no procedures?" she asked. The specialist shook her head. "No new meds?" The specialist explained that there would be medication changes, to better target the cause of her pain. The Dilaudid would also have to be tapered down over time. This is something that Emily had anticipated. "I can't go off the Dilaudid, it's the only thing I have that works" she said firmly. The specialist told her that there was a pharmacist at the clinic that would work with Emily to find something that works while decreasing the Dilaudid. There was also a psychologist that the Specialist wanted Emily to talk to in order learn about techniques to combat her pain. She explained to Emily that her pain's

origins were complex and they would need use multiple therapies in order to control it. With that, she stood and raised her hand to shake, and told Emily the psychologist would be in next to talk to her.

The psychologist was a brightly dressed woman in her late forties, she listened intently to Emily tell her story and asked questions at various points to clarify what had happened. She explained that she was going to run through some techniques Emily could use to combat her pain when it began to come for her. They covered breathing techniques, something called “mindfulness,” and relaxation of the muscles around her abdomen and pelvis. Emily was skeptical of these techniques but was happy to be focusing on things to lessen her pain. The final meeting of her appointment was with the pharmacist. The pharmacist was young woman in the drab grey dress and glasses of a professional. They discussed how the Dilaudid was going to be gradually decreased and that soon she would start a new medication called amitriptyline that had been shown to improve the type of pain Emily was having. By this point Emily was very excited to try new things that might help. On the drive home she found herself singing to her favorite song when it came on the radio, Tom Petty and the Heartbreaker’s “American Girl.” The sun was setting over the cornfields to her right, and she felt herself smiling for the first time in what seemed like years. She thought to herself that maybe she would paint tonight, paint these cornfields with the fading sun dancing through the tassels as it slipped past the horizon. She hadn’t painted in over a year.

The pain did not improve. The optimism Emily had felt on that ride home dissipated within two weeks. She tried the techniques she was taught. Focusing on fighting the pain almost made it worse. She had become so good at pushing it away on her own that the new techniques only made her focus on what was happening with her body. Decreasing the Dilaudid made her feel nauseous, but she knew she couldn't take more than the prescribed amount because she couldn't get more. She started taking another dose during the day and skipping the dose before bed, fighting to a fitful sleep late in the night. Then she tried taking one before bed and less during the day. She was a miserable wreck. The dulling effects of the medication were still present during much of the day, but she was now nauseous when she went without it. The doctors had her trapped in this cycle too. She had to go to the pain clinic all the way in Sioux Falls and see the pharmacist just to get her prescriptions. Soon, she began to hate the pain clinic and the torture they were putting her through. She tried to go to the emergency department in Ida Grove and explain to them the pain she was in, but they knew who she was and that she was not to get more medication. Then she went to a town about a half hour drive away, Denison. She told them she had had abdominal pain for a long time and she just needed something to get her home. The ER doctor told her he would be back in a moment. Emily saw him looking at a computer where he thought she couldn't see her. When he came back he explained they were not comfortable giving her any pain medication and that she should call her primary physician. Tears streamed past her cheeks as she walked out of the emergency room. On the drive home, as she passed every electric pole she imagined her car drifting over the edge of the road, bouncing through the ditch, and slamming into the pole. "It would be quick," she thought, "and rather painless." She grinned through tears at the word painless.

Suddenly she was pulling into her driveway however. She put her head on the steering wheel and sobbed as she remembered Jacob and his recent interest in her painting. They had set up a small easel next to mom's for him to paint at, although he needed permission to get the paints out. She took a few minutes and composed herself, got out of the car, and resumed the routine she had been living for two and half years now.

The Pain Clinic continued to taper her Dilaudid despite her protests. After several months, she started to notice a difference, and a small sprig of hope began to grow in her soul that maybe this could get better. Her pain was not any better, but the nausea had gone away without her noticing. Her thinking was clearer during the day. Her daughter Amelia, fifteen by this time, remarked that mom "wasn't acting so stoned." Her friendly snark had started to return. She continued to see the psychologist; fortunately Jeff's insurance paid for this. They continued to work on coping techniques, which Emily eventually learned how to apply to her own body in ways that worked. She was able to combat the pain with growing success. The specialist eventually convinced Emily, based on their other successes, to try a trial of an implantable spinal cord stimulator. She explained that the pain Emily was experiencing was generated in her abdomen and amplified abnormally in her brain. If they interfered with the signal coming from her abdomen, there was a good chance that her pain could be substantially reduced. Emily agreed to try this stimulator when she was assured that it would not require operating on her abdomen again. The specialist explained that on the day of the procedure, Emily would be placed on a table, and a needle would be inserted just like for the epidural she had when she gave birth to Jacob. This needle would contain the leads for the stimulator,

however. She would be woken up from the sedation and asked what she felt: when both her and the specialist were happy with the placement, she would be sedated again and the rest of the procedure would be finished. Emily had a lot of nervous energy going into the procedure room when the day finally came. This energy drifted away as she was lulled to sleep by the sedative. Suddenly she was awake again, on her stomach. The specialist asked her what she felt. It took a long moment for her to realize she felt nothing. There were no razor blades in her stomach. There was not even a hint of discomfort. Big drops of tears welled in her eyes as she told the specialist this. Before she could let out her emotion she was falling back asleep again. When she woke up in the recovery room she asked for the specialist and gave her a hug. As Jeff drove her home, she broke down in tears of joy. She still could not feel any pain. Jeff had called ahead to Amelia and when they got home the kids were waiting for her. She could not hold back tears as she hugged them. She lived in a state of bliss like this for several days. It was the most wondrous vacation she had ever experienced, she called it her "pain vacation." As the specialist explained to her before the procedure, it was unlikely that she would be pain free after placement of the stimulator. Her pain did come back, but it was much more manageable than before. She continued to take some medication, but was able to stop the Dilaudid, which had been both a friend and an enemy for so many years. It was almost like having an old friend move away; the memory she had of being on Dilaudid grew more distant as time moved on. She could barely remember what it was like to be on the Dilaudid after a few years. Her personality and wit came back slowly, and she was able to participate in activities at the school and in the community. She was rehired at GOMACO in an administrative role. She flew to Paris on September 16, 2018.

