



CHAPTER 1

Acknowledging What Happened

FOR YEARS, NOT just months, after Emma was incapacitated, I remember feeling like I'd been flattened by a hurricane, and that hurricane had washed away most of the landmarks in my life: most of our friends and family, most of our finances, and most of our happiness and hope. When I looked for hope by reading uplifting quotes, I would come across wisdom that sounded like this one:

Don't be the reason you're unhappy or not successful. If you don't know what's happening in life, make a change." Elle Sommer

What filled me was a pungent rage, borne of the feeling that life was being so unfairly nasty to me. Was this person dispensing a platitude that relegated my struggle to mindset rather than a series of unfortunate

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events, and daring to suggest that if I just changed myself, I'd be happy again? Yeah, my mental shift was a magic wand to undo the mistake that had turned all our lives into a lifetime of pressure, worry and fear. Instead of feeling empowered, I felt so empty and broken as I read quotes about happiness and the need to see the obstacle as the way.

The truth was that I didn't believe I could be honest about how I felt. I decided my family depended on me and so I had to be strong. With Sean's support, I had to figure out how to start seeing more positivity, even while realistically facing the lifelong challenges we would be navigating as a family.

As I look back and write this chapter these are the questions I ask myself:

1. Was I *genuinely* being strong as I put one foot in front of the other each day for years?
or
2. Was I only *pretending* to be strong?

To answer that, I believe I was doing both things simultaneously. I kept on living as we all must, come what may, and doing it because I needed to make an income to afford therapy and medical care for Emma in addition to the regular expenses of our life. I was also experiencing the strain, with a child who no longer slept at all during the day. Emma only slept for perhaps four interrupted hours each night, preferring to laugh and sing with me even at 3 a.m. and waiting for her daddy to feed her and sleep beside her (all of which still remains true eight years later).

My husband stalwartly slept beside Emma almost every night. He never complained and he never wanted to leave her side. He said to me once that we did not know how long she would be with us, and if anything ever happened, he wanted to know he had done all he could for her. I watched the physical, mental, and emotional strain

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take a toll on him. He endured headaches and we both suffered lower back pain. His once youthful face seemed to age in fast-forward. My heart broke watching the shift happen so rapidly.

Shortly after we returned home with Emma in her semi-comatose state, Sean and I talked about trying to balance challenges at work. I shifted my work hours to evenings and nights, in order to be able to keep my job and see to Em's medical and therapy needs during the day. About two years ago, we found a caregiver for Em whom we trust and fits like an extension of our family; she has made a huge difference as we have continued to shift into better life balance.

I found myself feeling lighter as I drove to work, because I was able to experience some hours where I functioned outside of the strain of Em's pain and worry about her future wellbeing. However, I sometimes had a sense of suspended reality, because my work and home lives felt unconnected and the disconnect made me feel inauthentic. I did not want to compartmentalise my life and, though it was difficult to speak about, I began sharing the details of what had happened openly at work.

That sharing made a big difference for me. As I learned to open up, I received many insights, opinions, and judgments from people with whom I was interacting. I received empathy and valued so much those people who held space for me. I also remember the advice from a co-worker to keep my personal life separate from my work life, because pretending all was well would improve people's perception of me. Processing that piece of advice was critical as it shaped my philosophy before I could move forward at work. Ultimately, I realised I could not give my best to anyone, unless I was presenting myself honestly. Though it is sometimes scary, it has also opened the door to allow healing, self-acceptance, and improved coherence in all the facets of my life.

Medical persons were advocating to "allow Em to go", to put her in a home and proceed with our lives, and even to plan a hysterectomy

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for her (it shocked and dismayed us that someone would bring this up for us when she was just 10 months old). On a daily basis, we were dealing with a good measure of guilt, fear, and worry. We had some added pressures as one or two family members called us incredulous about Em's brain injury. We found ourselves comforting and helping them accept that Em had been brain injured and bedridden. We also journeyed through sadness and roaring anger as some loved ones levied their opinions that we had caused Emma's injuries. Those experiences really shook me up. For a while, I gave in to the temptation to self-isolate and stop trusting others. Looking back, I recognise that people's judgments and opinions served a purpose: as painful as they were to navigate, they forced us to clarify our own positions and decide how we saw Emma and ourselves. We came to realise that no-one else's judgment mattered as we had to navigate the life we were living.

At the same time, our then six-year-old son was taking care of himself more than we realised. He brought home a report card in which he earned 100% in every single subject, and we were amazed and happy to have that unexpected boon. But not everything that looks shiny turns out to be good. I sadly learned a few years later that he was insisting on perfection from himself because he did not want to burden us more than we already were. He was constantly soothing and hovering over his sister. He was hugging us and speaking to us like a little parent. And I, walking through my life in a daze, recognised nothing off-balance until anger began to leak out of him a few years later.

There were also times I felt like I was witnessing God's miracles and an effervescent joy would fill me. One such time happened when I was doing a music therapy course to try to learn skills that I could parlay into daily support at home for Emma. I had gotten some plastic Easter eggs from the pharmacy and filled them with raw split peas (dhal) to make little shakers. Holding Emma's hand around a shaker, I had made up a little song and watched her squeal

in delight at the sound and vibration against her palm. I put the shaker on her highchair tabletop and swiped her hand at it. Her laughter filled my heart. Then silence, as I waited. Another swipe from me to get the rattle sound. Laughter. Silence. Then I said, “Emma’s turn.” Silence. Waiting. Up came her little hand, just by a few millimetres, but clearly an attempt to engage to get the sound. I shook the shaker and she joyfully laughed. Tears filled my eyes, and I couldn’t stop laughing. I kept it together and we took turns again and again, until the exercise ended in kisses and hugs and holding her close as I danced around and sang for her. She squealed in delight at the whirling movements.

How do you feel?

I share snippets of our experiences in the first few years following Emma’s injury because they chart the many lows the journey drags one through, but also remind you that there will also be some transcendent and unexpected highs that you will treasure forever.

I encourage you to hide from none of your feelings. You may find you put yourself in a sort of numb middle ground emotionally, because that keeps you from feeling the depth of pain, vitriol or anger set off by what you are experiencing. I believe that such numbing is a coping mechanism to help us survive the extreme pressure we may be under. The numbness may seem like a good thing and, in the short term, I think it is, but I don’t think it should become the state in which we live permanently. That’s because when you have joyful times, you may find that your numbness doesn’t let you truly feel it either. We need to find our way back to experiencing life fully.

Over time, I allowed myself to feel my negative and positive emotions more authentically, and that only happened in slow motion as I came to learn how to really cope with all the brokenness that

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lived inside me from experiences as far back as my early childhood and coming all the way up to when Emma was hurt and our journey from there.

My friend, I know that taking stock of how you feel is not likely a task that can happen in a single moment when you declare to yourself, “Let me face my feelings”. However, I want to encourage you to look within and get your feelings out for your own sake. Writing helps, or recording a voice recording on a phone. What happened? Where did it start going out of control? What is the last joyful moment you remember before things shifted? What marked the shift? What series of events followed? What was said to you? What did you say? What did you receive through your senses? What did you express using those senses? What thoughts did you have as things progressed? What feelings?

You don’t have to do this publicly; in fact, it may feel so much better to do this all by yourself. Just give yourself over and let yourself really feel your emotions. Sometimes, having a friend to talk to, or sharing the sense of loss with your spouse can be exactly right.

In my case, the first time I truly faced my pain was about a year after we returned home. Sean had gone to work, and I was taking care of Emma during the day; when he came home, he would assume duty and I would head off to my evening teaching. My back was hurting, and I was hunched over and dragging my right leg. Despite the pain, I had just lifted Em into the bathroom and bathed her and massaged her and dressed her and sung to her. Now I had her propped against my left arm as I fed her some milk.

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Suddenly I was crying: big wracking sobs as I told her how sorry I was that all of this had happened to her, how much I loved her and wished I could take away all this hurt and limitation from her. I just kept apologising and crying these big, open-mouthed

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sobs in the privacy of my home with the only witness being my blind, wordless child who could not see me cry or tell anyone what had happened. Without warning, Emma began to laugh so loudly and joyfully and the more I cried the more she laughed because, to her, my crying sounded like laughter.

I didn't discern the lesson then, but I have since thought back on it. There I was, labelling my child as "in pain" because I was measuring her against my standard of "normal" and finding her lacking. I was deriving my pain from the lens through which I was seeing our situation. But, even as I cried out of what I thought was empathy for her, did she really have pain? Not in that moment: just then, she had pure (and very loud) joy. I was projecting my pain because I was not yet being honest about what I felt. I needed to feel all those feelings honestly, and though I am writing about it, I know I have not finished my own tour of my emotions related to our journey with Emma.

I don't know what is to come, but thus far, I have felt such a range of lows, including "poor me", despair, frustration, begging God for a miracle, anger, isolation, jealousy as I watched other children cry loudly while my child could not make a sound, and bereftness as I watched a friend's seven-year-old daughter (also named Emma) walk about with her mom while Em remained bedridden at the same age. I have felt judged and belittled by doctors and therapists and family and strangers in clinics and on the street. I have doubted myself and hated myself for my weakness and my fear. I have taken out my frustration on my husband and even my son when the poison of self-blame has built up and erupted. I have cried in hopelessness and fear when Emma has been screaming from the pain due to her challenges.

And I feel shame, too. Once, an aunt and uncle showed up unannounced on my porch. I was still in my nightie at midmorning, bathing Emma and looking bedraggled. I felt so small before their eyes. I have felt abandoned by God and my family and friends more times than I can say. I have felt blamed and resentful, like the time

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an aunt told me it was my fault Emma was brain-injured because I opted for her to have surgery. I have cried and worried over finances, long-term care needs, a growing list of expensive equipment, risks of keeping Emma safe and also having a son to serve with dwindling funds, energy and time.

I have berated myself for not having it all together to a better degree. When I work on my business, I tell myself I should be doing more therapy with Emma. When I spend time with Emma, I tell myself I should be working on my business to change our financial situation. Sometimes the cycles of guilt are endless. Sometimes, I have felt so bone tired that I have wished it would all end so I can rest and then feel shame again because I am being so selfish.

And what of the highs? There have thankfully been those as well. I have felt the certainty that this life is a massive blessing because I have been able to share this journey with exactly the right family of souls who fit me and love me. I have felt my heart become buoyant with the lightness of Emma's laugh. I have sat holding Emma against my chest at 2 am and seen the glint of her bright eyes in the darkness and felt borne up by her absolute trust and love for me. I have felt motivated to be a better person because I think this challenge is pushing me to become stronger and serve others who are also on this sort of journey with their children. I have been inspired to create therapy materials and routines and songs and beats to serve Emma's needs. I have felt such fulfilment from that burgeoning creativity that I'm learning to ignore the voice inside that tells me to hide my voice and face because they are imperfect, and let those imperfections touch my child and others with love and trust and hope of service and inspiration.

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What should you do?

In line with the title of this chapter, my best advice to you is to allow yourself to really feel what you are living through with your child. Detail your situation as you lived it and felt it. Reflect on it. Lean into your emotions, both the low frequency ones that we label as “bad” and the high frequency ones that modern culture finds more acceptable. There is no shame in being angry, crying, talking to others, writing it out, or otherwise expressing your feelings. Get it out as long and as often as you need. If you have the financial ability, it might be a good idea to lean on a professional for trained support, or to enrol yourself in activities that could let you expel your emotions by getting physically active or creatively expressing yourself. Definitely, if you can, get help with the overwhelm of managing the multiple moving parts of your newly complexified home and work life. A competent caregiver, nurse, or assistant would be a blessing.

You are doing nothing wrong when you take some time for self-care; in fact, you’d be doing something very good not only for your health but also the health of your broader family.

At some point you will realise you aren’t stuck in the pain of the past quite as much, and you may feel more ready to assess where you are now. That is something so exciting to me because then you are ready to step back and look at the whole picture. Recognise that no matter how hard the past is (or the future will be), or how much pain we carry and feel because of it, that past is not in our control. The only control we have is in this current moment, so focus on accepting where you are, giving yourself a pat on the back, and recognising that past-you did the best you could have done.



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To conclude, settle into knowing that nobody else's judgement of you counts. What matters is what you think and what you feel in your current situation, and so I hope you are rounding up this chapter with a sense of readiness to look within. Face what you can face now and be gentle enough with yourself to admit what you can't face yet.

Your Checklist

- ✓ Be gentle with yourself about what happened.
 - Remember that we cannot change the past, but we can change our response to it; we can change how it affects us.

- ✓ Allow yourself to feel your feelings.
 - How did you feel then?
 - How do you feel now?
 - Both your positive and negative feelings are valid and important.
 - What are you not ready to open up to feeling yet? Revisit and tune in further over time.

- ✓ Try various tools and approaches to see how different ones may help you to connect with and process feelings at different times and in different ways.
 - Shout, cry to express anger, shame, fear, hate, jealousy, worry etc.
 - Talk with a trusted friend or counsellor.
 - Keep your insights private but explore them by journaling.
 - Get physically active.
 - Connect through your creativity.
 - Picture yourself as someone else that you are listening/talking to and being gentle toward.