

THE LITTLE DARK SPOT:

HOW I CAME TO TERMS WITH MY BABY'S STROKE



HELENE LOUISE

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*To all the children whose tiny triumphs are cause for celebration
and the adults whose hard work makes it all possible*

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Preface

All social change comes from the passion of individuals.

Margaret Mead

In writing this book, I can't claim to be setting out to achieve the kind of social change that Margaret Mead was probably referring to in this quote. However, in many ways her words resonate with my experience coming to terms with my daughter having suffered a stroke and my motivation for sharing our story. Receiving that terrible diagnosis and at the same time, being given a tremendously discouraging opinion as to what her future would look like, was one of a series of setbacks that marked the beginning of a very difficult period in my life—it was a time of great emotional pain, or *passion*, in the sense of “suffering” as it is sometimes defined.

One of the things that I think prolonged my suffering, is the emotional isolation I felt at that time. Had I been able to find a meaningful reference point to draw on, something to help me organize my thoughts and, most importantly, give me a sense of perspective and hope, I think that I could have come to terms with what I was facing much sooner than I did. Had that been the case, I think that I would also have been able to help my daughter even more than I have. But even now, many years later, there are very few materials available for parents in similar situations.

Perhaps that is simply because raising children is already challenging enough and when a child has a serious condition, there isn't much time left over to reflect on the experience, let alone document it so that it can be shared with others. In my case, however, writing about my experience has brought me a sense of healing and resolution. And, it is the very fact that I eventually found strength and beauty through such a difficult time that left me with a *passion* in the other sense of the word—in the sense of a “strong drive and feeling of conviction to do something”. If this book brings just a glimmer of hope and perspective to one person's life, then I will consider that my *passion*, in both the sense of “suffering” and “conviction to do something”, will have succeeded in bringing about a small change for the better.

Nevertheless, it is important to note that this story represents the individual *passion* of only one person—me. It is my version of a series of events and interactions as I experienced them. I recognize that the perspectives of those who were around me at the time may be different from what I have written here. Even so, what I have to offer is an honest account of how I felt when I found out that my baby had suffered a stroke, how my feelings about events and relationships at that time shaped my decisions, how I approached my daughter's rehabilitation, and eventually, how I came to terms with it all, realizing that even the most difficult situations can, with time, bring something positive.

If I could somehow reverse my daughter's stroke, I would do it in a heartbeat. But I can't and to my own relief, despite the emotional suffering of the past, there is much to be thankful for in the present. I greatly appreciate the support of the many professionals who have facilitated my daughter's rehabilitation such that her future is as bright as anyone else's. I am very thankful for all of my dear friends who helped me work through my emotional pain once

I managed to start talking about it and ultimately, have so generously supported me in my *passion* to transform my experience into something positive, beyond my own daughter's progress. I am thankful for my family and most of all, I am truly thankful for my daughters, from whom I have learned so much about love, compassion, forgiveness and understanding.

—Helene Louise

Introduction

My daughter Amelia (Mimi) was born on a beautiful fall day. She was the most adorable baby that I had seen since her sister Charlotte was born almost three years earlier. From the hospital window I could see the sun shining brightly through the brilliantly coloured trees. I was elated. I had two beautiful daughters, both in good health. I was married, I had a wonderful group of friends and I had a house with a small garden that I loved working in. I had much to be thankful for. In a way, Mimi's arrival signalled the realization of my lifelong dream. What I truly wanted most of all, was a happy and fulfilling family life. Somehow, with two children, my life seemed complete. We weren't just a couple. We weren't just a couple with a child. We were a couple with two daughters. We were a family.

From the day she was born, Mimi was a good-natured baby and overall, she seemed to be developing much in the same way as her older sister had at the same age. The only difference was that it seemed that Mimi might be left-handed. Because her father is left-handed, I didn't think much of it. But, as the months went by, I started to wonder if it wasn't that Mimi was favouring her left hand as much as it was that she was *only* using her left hand. With their spindly, uncoordinated

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limbs that flail around indiscriminately, and their tiny hands that they haven't yet learned to use, it's hard to gauge whether a baby is moving "normally" or not. Besides, there is so much else to focus on—the challenges of making sure that they are thriving, the relentless feeding and diapering routine and of course, the distracting happiness that comes from holding them close. But still, somewhere inside of me an uncomfortable concern began taking root.

A few months later, rather than starting to crawl, Mimi preferred to sit on the floor and push herself along sideways. We called it "scooching" and joked that Mimi was doing a great job of buffing the floors with her diaper. But, silently and steadily, the creeping roots of that uncomfortable concern continued to grow until finally, when Mimi was about eight months old, I asked my family doctor what she thought. After many tests, Mimi was diagnosed as having suffered a stroke—a "cerebrovascular accident". They called her condition "left hemiplegia". The specialist who gave me the news held up a blurry image and told me that it was a picture of Mimi's brain. He pointed to a little dark spot on the image and said that what it meant, was that at some point, a random clot had travelled to the end of an artery somewhere in my baby's brain and caused the damage which was that little dark spot.

I heard the words coming out of his mouth but they didn't make sense as they entered into my head. Why was he talking about something that happens to old people when I was there to talk about my baby? As far as I was concerned, strokes only happen to people of a "certain age", people who already have many vibrant years behind them and who, in those years, may have willingly lived with increased risk factors. Mimi didn't fit into that category. I had certainly spent the pregnancy doing everything that I possibly could to stay healthy, including exercising and maintaining a healthy diet. Mimi herself had, of course, never smoked or had a poor diet. She had barely

begun eating solid foods at all. Yet, there it was—a stroke was the specialist’s explanation for Mimi’s “scooching” and strong preference for her left hand. He went on to say that, as a result, Mimi would likely never walk and even if she ever did, it would be with a significant limp. Finally, he added that she would probably be developmentally delayed.

Through the waves of nausea that were now sweeping over me, I asked him desperately what I could do to help her. There was nothing to be done, he said, the stroke was permanent. But I couldn’t accept that answer so I continued to press him for options. The only advice he had to offer was that I should just “learn to live with it.” The finality of his words and the fact that they communicated a complete lack of hope was unbearable. But I couldn’t help it, I had to ask again if there wasn’t anything, anything at all, that I could do to at least *try* to help my baby. His response, more as an aside than anything else, was that if I really wanted to, I could try physiotherapy although in his opinion, it “wouldn’t be worth the trouble”.

Never in my life have I felt so overwhelmed and broken as I did at that moment. I couldn’t even begin to accept that there was nothing I could do to help my beautiful baby, even a little. I asked myself how the blurry picture of Mimi’s brain that he had just shown me could possibly mean, with all certainty, that my only option was to “learn to live with” the consequences of that little dark spot. This situation did not fit into my usual outlook of hopefulness even against the odds, and hard work even in the face of uncertainty.

As I tucked Mimi into her car seat to go home, she smiled happily at me. In my mind, I was frantically processing what I had just heard. But in my heart, I simply couldn’t reconcile the label and limitations that the specialist had placed on her with the intelligence and perceptiveness I saw in her bright eyes. I didn’t know what impact this would have on our lives and I had no idea what I was going to do about it. But, I knew with

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absolute certainty, that I couldn't accept the label and limitations as is and just "learn to live with it" as I had been told to do. Well, I might have to accept the label, because a stroke is a stroke after all. I had seen the picture that was now tucked away somewhere in Mimi's file and I had seen the spot that showed where the damage had been done by that wayward clot. But I didn't have to accept, and I simply could not accept, the limitations that had been placed on her, at least not without a good fight.

What followed was an intensely difficult period in my life as I struggled to learn more about what could be done for my daughter and what I could do to encourage her to achieve her full potential, whatever that might mean for her. It wasn't easy to gain access to the occupational and physiotherapists who could provide me with the guidance I needed. And, since I could find no relevant materials to inspire or motivate me, it felt as if I were searching for something in the dark without knowing exactly what it was that I was trying to find. After all, what was I aiming for when the specialist had told me that it wouldn't be worth the trouble to do anything?

I was desperate for a ray of hope, anything, however faint to which I could anchor my thoughts and actions in order to find my way. Through the many sleepless nights and anxiety-filled days that followed, the conversation with the specialist replayed over and over again in my mind. Gradually, I realized that ironically, the only semblance of a ray of hope lay within the specialist's own words. There was nothing positive about what he had said, of course, and he had been far from hopeful. Nevertheless, somewhere in the conversation that was looping in my mind, I started to focus on what might possibly be interpreted as an *element of doubt*. The specialist had said that Mimi would likely never walk. Maybe, "likely never" didn't necessarily mean "absolutely for certain she will never walk". He had said that she would probably be developmentally

delayed. Maybe, “probably” didn’t necessarily mean “absolutely for certain she will be developmentally delayed”. Admittedly, it was weak as far as rays of hope go but in the absence of anything else, it was all that I had to go on and it would have to do.

So, not long after that appointment, I started working hard to help Mimi learn to walk despite what the specialist had told me. I came up with different ways to help her learn to keep her balance although it was clearly much more difficult for her to do so. I held her tiny hands in mine and smiled at her encouragingly. At the same time, I held in my fear and pain, and when I simply couldn’t hold the tears back any longer, I would turn around, let the most rebellious ones escape, wipe them away, turn back around and keep on smiling at my happy baby. Mimi didn’t know that there was a problem and, as much as I could, I was not going to contaminate her childhood with something as heavy as this. If it turned out one day that the specialist was right about everything, I would worry about that then. In the meantime, Mimi was a happy baby and I was going to keep it that way.

To my great amazement, with a lot of patience and perseverance, and a lot of tears wiped away so that no one could see, Mimi made progress. She was wobbly and she did limp but she could balance herself and put one foot in front of the other to get wherever she wanted to go. She could walk—absolutely and with all certainty. In the absence of a reference point for what was possible, this development magnified my faint ray of hope into a *reason to persevere*. It reinforced my commitment to helping my daughter as much as I could. Maybe, even if I hadn’t tried to help her in the way that I did, she would have learned to walk just the same. But the fact that the specialist had said that she likely never would and then she had learned anyway, set me on a path to believe in her and always question those who said that she wouldn’t be able to do something.

As a result, I worked hard to get the advice that I needed to understand her situation and figure out how I might help her. Whenever I was told that something wasn't possible for her to do, I asked, "What if it *were* possible, what could I do then?" I pushed against all kinds of negativity and I never gave up on my commitment to help her achieve whatever her own potential might be. Each step of the way, Mimi continued to surprise everyone with her brilliant determination, endless creativity and tremendous capacity to overcome the limitations placed on her. As almost imperceptible as each step towards improvement was, each one was a tiny triumph and each one was something to be appreciated and celebrated.

Now, ten years later, Mimi is a vibrant young girl who is doing fine in school, enjoys sports, plays the violin and is fully fluent in both English and French. She has exceeded all expectations. She knows how to work hard, she knows what it is to overcome challenges, she is confident and she has a strong sense of self. Most of all, she does not define herself in terms of the effects of that little dark spot. Some of those effects are still there and we're still working on them but compared to where we started, we have come a long way from that devastating appointment with the specialist.

As it turns out, despite the emotional pain and difficulties of the past ten years, there has been much to be thankful for. Along with the heartbreak, there has been hope, inspiration and success. Within the struggles and triumphs, no matter how ever-so-tiny those triumphs may appear to others, there has been beauty and grace. Had I known what was possible with patience and perseverance and how much hope there actually was, this journey would have been much less difficult. Had I had the benefit of someone sharing their experience with me—a story in which I could recognize my own feelings—this journey would have been much less isolating. It is with this in mind that I have written this book.

Initially, my objective was only to document how I dealt with my daughter's stroke in terms of the things I think I have done well and the things that I might have done differently, had I known then what I know now. However, as I started writing, I realized that I could not separate the way in which I dealt with this experience from everything else I had to cope with over that same period of time. The other major challenges, including the unravelling of my marriage, influenced the choices that were available to me. Under different circumstances, with different options, I may have done things differently. Because of that, what I am offering here is a much more personal account than I ever intended to share.

This is the story of how I came to terms with my daughter's stroke in the context in which I dealt with it. I hope that by honestly describing my experience, parents in similar situations may find their own feelings validated such that they can focus more clearly on the future and on achieving the best possible outcome for their child, whatever that means for them. And, even for those who are not facing a similar situation, in sharing the tiny and not-so-tiny triumphs that were ours to celebrate, perhaps they too will be inspired to persevere and focus on what is possible, rather than what is not.