

TWO STEPS FORWARD

*Embracing life with a
brain tumor*

SAMPLE CHAPTER



CLAIRE SNYMAN

This book is not intended as a substitute for the medical advice of physicians. The reader should regularly consult a physician in matters relating to his/her health and particularly with respect to any symptoms that may require diagnosis or medical attention.

Twenty One

BEING A PARENT

I WANTED TO WRITE THESE WORDS FOR THOSE OF YOU WHO may have young children when you are first diagnosed with a health condition. It adds another layer to the paradigm. My first thoughts after diagnosis were of my son and husband. Would I live to see my son grow up? When I got home after being in the ER, Aiden was sound asleep. I remember watching him sleeping, only four years old and all pink-cheeked, oblivious to the goings-on around him. My heart literally felt sore, almost shattered, inside my chest. As parents, we will do anything to protect our children; it really is a primal instinct.

Here are some of my lessons:

Telling your children

Whether and how to broach your health condition with your children is a very personal decision. It depends on the age of the children, and how much they can take on board.

Children differ greatly in their individual natures as well as in their maturity. They seem to be very matter-of-fact about a lot of things of

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this nature. It's similar to the 'sex' talk—they take on as much as their brains and emotional state and maturity are able to at the time. The rest tends to glide over their heads and seems irrelevant. It's almost a protective mechanism.

Aiden was only four years old when everything first happened. He was too young to really understand events, so we did not discuss my tumor with him. He just knew that Mom was sick and would be at home, getting better.

From a practical perspective, Aiden knew from preschool what an emergency looked like and how to dial 911. After my diagnosis we reinforced this with him, just to be on the safe side. In August 2012, when I started to get acutely ill and developed hydrocephalus, we were transparent with Aiden about any tests I was having. But we did not show fear to him; rather we told him that we were doing tests to ensure that everything was okay.

When I was finally diagnosed with hydrocephalus and we had to leave for the surgery in Baltimore, Aiden was six years old. He was more able to grasp what was going on around him, but was still only a young child. We did tell him that Mom was going to have surgery to make her better, but didn't provide specific details.

Hospital visits

Looking back, it amazes me at how resilient kids are. To this day, if we ask Aiden what one of his best holidays was, he will reply, "Baltimore, when Mom had brain surgery." Who would have thought? I still giggle about it. He had Granny there, he stayed in a great hotel, which had a pool, and he went to cool museums, had cool food and missed school. Awesome! Aiden and I did not see each other for four days as he could not visit the ICU. On the day I did walk out the ICU to see him, he was terrified and jumped into Marchand's arms. I realized that the reality was too much for him.

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So perhaps taking kids to the hospital to visit, especially really young kids, should be discussed. Not many adults, let alone kids, feel comfortable in an ICU setting. It can be traumatic to see a parent attached to IVs or things they do not understand. Keeping in touch by phone is a good option. Hearing mom or dad's voice reassures children that everything is all right. Aiden did not come back to the hospital again, even when I was readmitted with meningitis—it was just easier to speak on the phone, and better for him in the long run.

Your children's emotions

One thing we did notice during my surgery and re-admittance to hospital, then coming home and going back to school, was that Aiden got more nervous than usual when he sensed change was coming. This made total sense, given everything he had been through in the past month. So, we took extra care to be mindful of this over the next while and with time, he was back to his normal self.

Children sometimes react very differently to how we would expect them to react in these types of situations because we are expecting an adult reaction. So keep an eye out for changes in behavior—this could be your child's way of expressing their emotions, and it might not be what you expect.

Post-surgical changes

For me, as a parent, the bigger challenge was actually in the recovery after surgery and not the diagnosis. The immense and sometime crippling fatigue and prolonged recovery was hard, as I struggled to get back to being a mom and a wife. For the first two months post-surgery, when I was heavily fatigued, I needed help fetching him from school and caring for him. It also meant explaining to a six-year-old what it meant for Mom to not be firing on all cylinders. Impatience

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and frustration were common feelings, and I had to ask for Aiden's help to get through it all.

It was important for him to know that it was not his fault that Mom turned into a 'monster' by 5pm—her body was just so tired, and small things were really sapping her energy. Organizing play dates with good friends after school or on the weekend was an integral part to helping Aiden feel like life was good and things were moving forward. It also made me feel better, as I knew he was happy. At the innocent age of six, life is simple. The more things moved forward in a routine, the better things went for everyone.

I cannot deny there were moments when I lost it as a parent. When Aiden threw comments back to me, that cut deep. There were times when the exhaustion and frustration of my recovery went down to my bones and barely allowed me to function, let alone be the loving and patient mom I needed to be. I knew Aiden resented my brain surgery and my fatigue, especially when I could not keep up with his demands and do things that other parents could do.

My words of advice for parents who are recovering from brain surgery, or major surgery of any kind, is to find small moments and relish them. There may be many times you feel inadequate as a mom or a dad or caregiver, times when your fatigue overwhelms you. You might become grumpier through frustration or impatience. By the end of the day, you might even feel guilty.

Take five minutes each day when you do have the energy to revel in the love you have with your child. Just be with them and do whatever it is that they want to do. Let them feel all that attention just for them, in that moment, so that when it starts to unravel at the end of the day, they remember subconsciously the moment you shared.

Also, find a few things that you can do with them, e.g. build a puzzle, read a book—things that do not fracture your energy. Another lesson for me was to ensure that I made peace with Aiden at the end of each

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day. Fatigue meant that my tolerance level after surgery was very different. Sometimes, by the end of the day I felt like I had left the day on a bad note with Aiden—in my mind, not necessarily in reality.

Wipe the slate clean

Because I went to bed so early, almost straight after he did, I missed out on that incredibly special moment I used to relish, that moment of peeking in on him sleeping. Even now that is one of the most special parts of my day. It is the moment I remember what a miracle he is and how very blessed we are, and it fills my heart up for the next day. No matter what the day held for us both, this is the clean slate, the white flag. The next day dawns anew. So, I make sure now to always go in and wipe the slate clean, and be thankful for my miracle and kiss his soft cheek goodnight.

Confidence in your parenting

My confidence as a mom has definitely been rocked during this adventure. I had to rely on other people to be ‘mom’ to Aiden for at least the first two months post op. When I was back in that role yet struggling with extreme fatigue and the resulting irritability and impatience, at times I felt like I was an incompetent mom. Not that I could not look after him; that was not the issue. It was more that I couldn’t always be the mom I wanted to be: patient, kind and understanding. That was hard for me, especially by the end of the day.

I found initially that I would get unusually stressed about play dates. I have realized that a lot of this is related to the fact that in the initial months, I had to rely on so many other people to take on tasks I used to consider easy to do and just part of every day. My stamina and faith in my abilities had been taxed so many times that I questioned my ability with certain things. I also found that I was oversensitive to Aiden’s antics as an energetic seven-year-old. Because my energy levels

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were so linked to my patience and tolerance as a mom, I overreacted to him being naughty, trying to protect myself from getting fatigued. I am now aware of this being a negative issue, and one that I used as a coping strategy. If Aiden was playing up, I would rather pack up and leave than battle it out—it was too tiring for me. I found it better to be open with other moms around me when I felt I was getting oversensitive about his antics. I let them know that I hope I didn't seem irritable or oversensitive, but that my brain sometimes struggled to find the balance between managing my energy levels and being a mom. I did this not to gain sympathy, but to inform them and decrease my own stress as well.

As a side note, I found that around one year post surgery, the issues with stress and confidence improved dramatically. By eighteen months post-op, things were mostly back to normal. I think this has a lot to do with the decreased fatigue and improved short-term memory that came with passing that 'one year' post-op mark. My local neurosurgeon said it would make a huge difference, and he was right!

With my second round of medical appointments and my potential second brain surgery, we were very open with Aiden about what was going on. I think this worked well, as he was now seven-and-a-half years old.

One day I was on the phone to the doctor in the United States and they told me I might not be able to get an appointment for three months. I told them I was not able to work due to my symptoms and, after completing my call, I put down the phone and wept in sheer frustration. Aiden came up to me and put his arms around me and gave me a hug, saying, "It's okay, Mom, it will be alright." I was taken aback by his empathy and felt humbled by his maturity. Your children can surprise you in the oddest moments.

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Connections

Looking back, I think the best thing is to be as honest as you feel necessary, keeping in mind your child's capability to accept the facts. Love them, respect them and talk to them while still keeping the adult role model present for them to see that someone is in control. This is important and offers them a sense of stability and safety in the home environment. When you are not having a good day, they may surprise you with how much they understand and empathize. At the same time, they are simple beings. Depending on their age, they may not need a plethora of information, so tell them things only as they need to know. For me, the physical connection was challenging as my body was weak and fatigued. Remember to give those hugs and kisses and maintain the physical connection as much as possible if that is an important part of your relationship. I found months later that it was as if with the surgery, this connection had been severed as well. With time and my energy, this returned and with it my son's realization that mom was still here.

At the end of the day, let us be grateful for these wonderful beings.

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Thanks for reading, I hope you enjoyed it! With gratitude Claire

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