

TWO STEPS FORWARD

*Embracing life with a
brain tumor*

SAMPLE CHAPTER



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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.

One

SHOCKWAVE

14 May 2010

Stop spinning, is my first thought. As my head comes off the pillow on waking, the light fixture above me is moving in circles. This is crazy... let me stand up. Not a good idea...this is worse than having drunk too much wine without enjoying the occasion. What is going on? Oh my goodness, I feel sick. Sick to my stomach. It is 6 am, according to my phone, which lies dancing on the bedside table beside me.

I cannot stand up without holding onto something, or the merry-go-round makes me fall over. I stumble to the washroom just in time and grasp the toilet bowl as the room continues to spin around me. It is early morning and I can hear the sounds of life downstairs. I feel terrible. I am normally a get-up-and-go person. Normally the alarm goes off and I am out of bed. Not this morning.

It is only twenty minutes later per the clock, but it feels like hours to me. The room is starting to spin at a slower rate, but the nausea still clings to me like a sheen of sweat. I stumble downstairs, hanging on to

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the stair railing, to tell my husband, Marchand, that work is definitely a no go for me today. It must be some virus, and please can he take our four-year-old son to preschool? Okay, time to get to bed and sleep this off...except that lying down seems to make the spinning worse. I cling to the side of the bed like a life raft. The overhead light hanging from the ceiling becomes my point of focus, the compass that tells me that things are slowing down and the room is spinning slower. My exhausted body takes over, my eyes close and I sleep...

When I wake I am still feeling very lethargic, as if I have just completed a half marathon. Gee whiz, that was not a great introduction to vertigo—assuming that is what it was. I am hoping that is the last that I see of it! It must be a combination of this virus as well as just being really busy. I work full time as the international marketing manager at a local biotech company. I love my job. I love being a mom and a wife. But I am tired overall. This is probably just an accumulation of everything, my body's way of telling me to look at the stop sign in front of me. I am a perfectionist, a Type A personality, and always push myself to the limit, wanting to get everything and more done in the time frame I set myself. Not surprised that I feel so terrible today. It's been hectic!

17 May 2010

After spending the last two days in bed recovering from that vertigo attack I have decided to visit my GP, as I have now developed a massive headache. The vertigo has gone, thank goodness, but I am still feeling off balance. I feel hungover. I have been working from home rather than heading into the office and infecting anyone else with whatever it is I am harboring in my body.

I have never been someone who suffers from headaches, so this is a new thing. My husband gets bad sinus headaches and migraines and I have never really understood how painful and debilitating they are. The “crawl into a dark room under the bed covers” advice seems absolutely

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right. The light is too bright for me; even the weak sunlight today is painful. My GP has advised that, given the sudden onset of all these symptoms and the fact that I have never been a headache sufferer, I should go to the local ER if it does not resolve over the next day.

18 May 2010

I feel worse. My husband urges me to head straight to the ER. I call my doctor's office and they agree—they want me to be checked out for meningitis. So off I go. On arrival I explain that my GP thinks I might have meningitis. I am promptly handed a facemask. Funny how people don't sit next to you when you are wearing one of those blue masks. I don't care; I just want to feel better. I am admitted in the ER and my veins are exposed to needles for blood tests, as well as an IV to get some fluids coursing through my body. The doctor orders a CT (computerized tomography¹) scan and a lumbar puncture to see if there is anything to explain the onset of these symptoms. As I am lying on the CT scan table, staring up at the roof, which has maple leaves on it, I think, what if I have something in my head that is not supposed to be there?

I am back in my ER bed, waiting for any news from the doctor, when my husband arrives. What a star he is. I wasn't expecting to see him. But I do feel relieved to have someone I know nearby. He heads off to get a quick coffee. I listen to what is going on around me in the ER: always so much on the go, patients talking, groaning, doctors, nurses, questions, answers. I hear the doctors talking down the hall about a brain tumor and saying that it is quite unusual and rare. There seem to be quite a few people discussing it and looking at the scans, and I think: "What a thing for that person". Little did I know that they were talking about me.

1 CT scan combines a series of X-ray views taken from many different angles and computer processing to create cross-sectional images of the bones and soft tissues inside your body <http://www.mayoclinic.org/tests-procedures/ct-scan/basics/definition/prc-20014610>

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Tick tock, goes the slow clock inside the ER.

Eventually the doctor arrives to talk to me but Marchand is still out, so I am alone when the doctor tells me: “We still need to do a lumbar puncture to check for meningitis, but the CT scan found that you have a colloid cyst in your brain.”

What? My heart stops. Are you kidding? A *what* in my brain?

“Don’t worry,” he says. “The colloid cyst is often an incidental finding and we don’t think it is causing your symptoms, but we will get a neurosurgeon to come down and see you to chat further about managing it.” And he leaves.

I take a deep breath. Oh my gosh. My pulse races. I pull out my phone—screw any rules about cell phones in the ER—and rapidly Google: Colloid Cyst. I scan the information and read that it is a non-malignant brain tumor of sorts in the third ventricle of the brain, and it can require brain surgery if it is problematic.

“Approximately three people per million per year receive a diagnosis of a colloid cyst,”² I read. “Approximately 0.1-1% of all primary brain tumors and 15-20% of all intraventricular masses are colloid cysts.”³ “On rare occasions, a colloid cyst may obstruct the foramen of Monro completely and irreversibly, resulting in sudden loss of consciousness and, if patients are not treated, coma and subsequent death due to herniation.”⁴

That is all I can read before Marchand walks back in smiling with his coffee: “Any news?”

How do I do this? How do I tell my husband that I have a brain tumor, albeit benign and non-malignant? I almost want to laugh. I am still digesting the information myself. So I just do it: “They think I may have viral meningitis and are going to do a lumbar puncture to check.

2 <http://radiology.rsna.org/content/239/3/650.full>

3 <http://emedicine.medscape.com/article/249401-overview#a0199>

4 <http://emedicine.medscape.com/article/249401-overview#a0112>

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And they also found a brain tumor on the CT scan. It's not malignant." I stop. I just don't know what to do.

I see his eyes brim with tears. "You are kidding, right?"

I feel numb. Given that we know so little, there is no point in having a panic attack right now, so we wait. We just hold hands in silence and wait for the neurosurgeon. I lie there in the emergency room with a thousand thoughts flying through my mind. I oscillate between wanting to laugh hysterically or cry out loud.

Shortly thereafter, the doctor comes in to do my lumbar puncture and then we wait. About an hour later, we finally meet the neurosurgeon. A neurosurgeon has always been one of those godly specialists that I never thought I would have to meet, especially to have a look at my own brain. This seems surreal on so many levels. He tells us that I will have an MRI (magnetic resonance imaging)⁵ in about two weeks, so they can see the cyst in more detail. He tell us that most people live their lives without ever having any issues with the cyst, and that they doubt my current symptoms are caused by it, although at one centimeter, it is medium to large in size.

They will monitor me yearly with MRIs to see if the cyst grows.

The lumbar puncture reveals that I most likely have viral meningitis. Viral meningitis has similar symptoms to bacterial meningitis but for the most part is not as deadly or as debilitating⁶. There is no specific treatment and I will just require rest and some tender loving care at home, then I should start to feel better.

Okay, let's go home. I feel numb, in my back from being stabbed for the lumbar puncture, in my arms from the drips, and in the rest of my body and mind from the shock of my other diagnosis.

5 MRI is a technique that uses a magnetic field and radio waves to create detailed images of the organs and tissues within your body. <http://www.mayoclinic.org/tests-procedures/mri/basics/definition/prc-20012903>

6 <http://www.nmaus.org/disease-prevention-information/is-it-viral-bacterial-or-fungal/>

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I have been in the ER all day, so our kind neighbor has looked after Aiden and now our babysitter has tucked him up in bed. I walk in on him fast asleep and my heart feels torn in pieces as I see his little chest move up and down. My little man, only four years old, my miracle for whom I would do anything, lies blissfully unaware of the torment in my mind and heart.

I wait till the timing is decent and call my parents in South Africa, tens of thousands of kilometers away, to tell them about our day. I really don't have too much to tell them, given that I am still coming to terms with it and don't know more than what I was told today in the ER.

That night I search more online to understand what a colloid cyst is and what it means. There is not a load of information, but I hope the next weeks will reveal more information and medical research about this condition. It is now 11 pm and dark outside. I hold onto my husband like a life raft and let the flood of tears from the day pour down my face. It is the eighteenth of May 2010.

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

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