

# A STROKE OF LUCK

A GIRL'S SECOND CHANCE AT LIFE

BY

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*(sample)*

## The Worst Day of Our Lives

Bringing Alex to surgery is different this time. I am always allowed to go in with her and hold her as she is put under. I am to go in with her this time as well. However, this time it is so tough for her to talk. She holds on tight but she doesn't talk much. She still tries to say Panda's name as she is going under because that's whom she will dream about, but she can hardly even say his name because of what the Haldol is doing to her.

Marc, my dad, and I are brought to a special area to wait for Alex to come out of surgery. Other families wait there too. The hospital is not just for pediatric patients, although Alex is in the pediatric ICU. This area is for everyone. Most people are clearly waiting for older patients. It is so unfair that Alex has to go through so much at such a young age.

We wait and wait. The surgery takes many hours. The surgery starts with an MRI, then Alex's skull is secured in a frame so that the placement of the deep brain stimulator will be exact. The stimulator wire is placed and then Alex has another MRI to check the accuracy of its placement. The battery is placed in Alex's chest and a shunt is used to connect the wire from the top of her brain around and down her neck to the battery. The battery is typically placed in a second surgery but we don't have the luxury to wait in Alex's case. The battery is placed at the same time so programming the DBS can commence immediately. The doctor decides to use a rechargeable battery. We will need to charge it every few weeks by placing the charger over her chest for an hour or so. While a hassle, she will not need to have surgery to replace the battery for seven to nine years as opposed to every three years for a nonrechargeable battery. That is a good thing. When the battery is replaced, it will mean surgery on her chest area not her brain. Having brain surgery just seems so wrong.

The DBS requires a change in Alex's lifestyle. She will be limited in some ways. She can not be around large magnets. She will not be able to go through airport security like everyone else. She will even need to be careful going through the security devices at department stores and libraries as they can turn off her DBS. She cannot have an MRI on any part of her body but her head and it cannot be the strongest MRI. The list goes on. It feels strange to read the list, almost surreal. It is daunting but necessary. Alex is in surgery to have the DBS placed because we have no other options.

Once Dr. Alden is satisfied with the placement of the DBS, the incision in Alex's scalp is closed back up and Alex is brought out of anesthesia. We get a few updates during the surgery; things seem to be going well. I feel like I am holding my breath all day long. We are basically silent the entire day.

Dr. Alden finally comes in with great news. Alex's surgery went beautifully. The placement of the wire is just perfect. The shunt was very difficult to pass to connect the wire to the battery but all is good. We should all be thankful. We are. We will be able to see her in forty-five minutes.

We are thrilled. We all get on our cell phones and email, contacting everyone we know. Alex's surgery went well! My mom is chaperoning Jessica's all-day field trip to St. Augustine, Florida. She's been on pins and needles all day. We chose to not tell Jessica about the surgery so my mom has been worrying all day in isolation. My dad calls her immediately. Marc calls his parents. I call my sister. We are so relieved. Now we just have to wait for Alex to wake up.

We wait and wait—much longer than 45 minutes—and nobody comes to get us. Have they forgotten about us? Is Alex lying in recovery without us? I ask questions of the people in the surgery waiting area but nobody has any information. Dr. Alden comes back. He looks grave.

He says, "Things are not good." I will never forget his face or those words. When they tried to wake Alex it was difficult. Then they looked at her eyes and her left pupil was blown – dilated in a way indicative of a brain trauma. She had a brain bleed to the left hemisphere of her brain and it isn't good.

Dr. Alden explains they will need to remove a section of her skull to release the pressure and get the blood out. They will leave the skull out so her brain will have room to swell. He says it is very serious, he cannot anticipate the result. She might not survive. He says he needs to do it immediately. Dr. Alden asks if we have questions. He directs this question to me, clearly anticipating that I will have questions. I always have questions. This time I just say, "No, just go to her. Please help her."

He leaves and we wait and cry. We are panicked. How can this be happening? Things had gone well. What went wrong?

We have to call our family again and give them the bad news. It is tough to even speak through our tears but they have to know. My poor mother has to handle the news while chaperoning Jessica's field trip. I don't know how she is possibly able to hold it together without letting Jessica know.

It is Jessica's birthday.

## Hot Potato (by Jessica Dixon)

Mom was on a work trip then the next thing you know Alex is picked up by Grandma to go fly to a hospital then to my shock they are back the next day. Right after that Alex is stolen from me again. I just watch Alex and Dad pack the car feeling left out. I wish I could go too but what help would me going be? Alex is always kind of sad nowadays. It is like she gave up on life. Yet, my brave older sister still puts on a mask to hide the pain around me. She pretends it is all good and sits down to play dolls with me. Dolls were almost all we played once her illness started since she could no longer play outside. Still I can see through it. Most of all I can see it in her eyes. Her eyes are always sad now. They are missing that familiar twinkle of heart and happiness. The muffled sobbing in her room at night lets me know as well. What scared me really bad that showed how much pain she was in at the time is when I accidentally touched her bad leg. She started crying like the time she broke her elbow but the way she cried it sounded like she was in worse pain than that.

Mom, Alex, and Dad left me with Grandma and Grandpa. Dad and Grandma go back and forth a lot. I wonder if the clinic is working. Well of course it would work. It is an RSD clinic after all. To me at least, it almost seems like it is made for my big sister. My grandparents said I might get to visit Alex and Mom soon. I hope so and I hope this is the longest I will be without them. Grandma said that we are going to visit my Aunt Marni in Maryland. I miss my cousin Taylor but I would much rather see Alex. I feel like I am going to go on a vacation. They pretend it is one, but in my heart I know the truth. They don't know what to do with me. I almost feel like a hot potato. I feel like something that they can't keep for long, or don't want to keep for long. For me a vacation is a break not a distraction from the truth. It is something I rather not do alone but with my family. This is not a vacation but something to keep me from the drama and pain. That causes me to feel pained and abandoned. I wish they knew it doesn't help. I wish I could be with them. What they don't understand is that knowing the cold hard truth is better than being in the dark. They will heal Alex without me being a part of it or even being there. That's enough to ruin someone's "vacation" right?

When I get to Maryland I have a lot of fun. I go ice skating, and to the beach! I go to see Aunt Marni's house for the first time since I was a baby! Taylor is so lucky! She has a bird named Perry, a bunch of fish, a basement filled with arcade games, and a beach house. I know I am luckier, Taylor doesn't have a sister and I have the best one of all.

Alex will even get to run and play with me after the clinic. Alex and me used to invite people from the neighborhood and play freeze tag. When she comes home we

will push each other on the swing and jump off when Mom's not looking. Maybe we will even invite the boy we both have a MAJOR crush on to play with us. Just like the old times. I remember like it was yesterday when Alex was going to the doctors because of her back pain. I also remember in painful clarity when I came inside from playing with my neighbor on the swing set. When I came in my dad was waiting there with an arm to cry on and the news that Alex was in the hospital. It was only the start of bad news. One of the worst memories I have is visiting my happy, beautiful Alex at the hospital but there she wasn't happy and she was still beautiful on the outside but missing that inner glow. She was a shadow of her former self. She was an empty shell. Alex was missing that spark of life. Now she is surviving without living and wishing she wasn't surviving. That will all change when she is done with the clinic.

I leave Aunt Marni's to go visit Alex. By now I am sick of the driving. It was a seventeen-hour drive to Maryland and the next thing you know I am off to somewhere else. I get so carsick I have to bring a pail to throw up in. It is a cute purple-colored sand bucket that smells like puke. No matter how many times we wash it that smell never comes out. It is supposed to keep me from throwing up all over the car but there have been some mishaps. Mom's car often smells like the bucket. It is fondly referred to as the "puke bucket." I had to use that bucket four times on my drive up and after this trip I will have to drive back home. I still want to see Alex and see how she improved. I wonder if she is out of her wheelchair.

When I get there I meet Zombie Alex. Her spark has done more than died. The spark froze. She is tired and skinny. If you saw her without knowing her she would look dreadfully ill. In a way she is dreadfully ill. She hops rather than walks to get around and looks like she really needs a wheelchair. That fire of hope inside of me is devoured by disappointment. All that is left is a small flicker. The undoubted idea of a full recovery becomes much more doubted. If anything Alex looks worse. But maybe it will work I tell myself. I continue to lie to spare my heart.

When I get to the hotel I really like it. It is more like home than our own house at the moment. People say home is where the heart is. That is true. My heart lies with my family so where my family is, my home is. The suite is cozy and themed in a deep blue color. Pictures of our family are pinned to the walls. This place has more pictures of Alex and me on the walls than our house. I guess they miss me as much as I miss them. It is nice to know they think about me, but it doesn't help much when I want them to be with me. I like the view and it serves as a minihouse. It doesn't feel like a hotel room. There is more of a connection to this cluster of rooms than an average hotel room.

I love sharing a room with Alex. It is the first time Alex and I share a room since the townhouse we rented before we moved to our house. Even though she is an empty shell I still love that shell. Even though it isn't truly Alex it is more of her than I had for a while and I cherish it. I also really miss Mom and Dad. For the rest of that day I am flipping over from disappointment to joy.

I am pleased to find a fish in the suite. Mom and Zombie Alex bought a deep blue beta fish to keep them company. It fits in just right, matching the color and feel of the room. Alex leaves to go to the clinic each morning. It sounds like torture, but it is made for my sister to get better so maybe it is Alex just being reluctant. After Mom and Alex get home from the clinic we go to the pet store. I am going to get a beta fish and I will get a cute tank just like Alex's. The beta fish is a beautiful deep blue with a top fin colored a brilliant red. It stands out among the beta fish with fin disease and incompatible coloring. I just have to have it. So I pick up the beautiful fish's bag with poop filled water and buy it.

Mom has to run to a department store to buy something. We are in the middle of the store when some of the poop water gets on me. Not only do I puke when I get car-sick I puke when things are gross. I find that gross and puke in the middle of the store. I just sit there watching the frantic rush of my mother trying to clean up my mess with paper towels. If I didn't still have poop water on me I would find it funny. We leave the bag with the fish at the hotel and we go out to dinner. I don't like most of the meals on the menu. My mom thinks I will like Caesar salad so she orders it for me. Now my beautiful fish is still without a name. I really like this Caesar salad. Our waitress comes to our table to see if we need anything and I tell her what my fish's name is. I named it Caesar. The young waitress eager to listen to the cute eight-year-old (who looks more like five) asks if I named it after the Roman leader. Jokes on her, I named it after my new favorite salad.

I have to leave my family again. I can only spend a week with them. In this one week I am able to get a fish and visit the aquarium. I will really miss my family. Now I am leaving in the car. I am reacquainting with the "puke bucket." I might be away from my family now, but I will be with them when my fully recovered sister comes back. Well, at least I tell myself that.