

Emotions, Chaos and Commotion

A Family Narrative

You cannot imagine how time. . . can be. . .so still.
It hangs. It weighs. And yet there is so little of it.
It goes so slowly, and yet it is so scarce.
If I were writing this scene, it would last a full fifteen minutes.
I would lie here, and you would sit there.

Wit by Margaret Edson

My Dad had been having headaches. One night as we turned onto West St., he said, "It's probably brain tumors!" with his big goofy grin.

A few months later, on Aug. 9th, a Monday, Dad went to "get his cat scanned." That night, we sat around our kitchen table.

A week later we knew:

It was in the middle of the middle of his brain.

It was the size of three golf balls.

It was malignant.

It was inoperable.

It would not respond to radiation.

And no one had ever seen this type of tumor in this part of the brain before.

He was immediately sent to Mayo Hospital, three hours from our home. "I finally won the lottery," Dad would tell people, "Just the wrong one!"

Even though it was inoperable, they knew he would die if they didn't. That's one of the few things they did know. I wasn't there, but I love imagining the scene where the doctors tell my Mom and Dad about doing the surgery:

"We'd give you the odds, but we've never seen this before, so we've never done this surgery before. You are the statistic. You could die, you could be fine. You could be blind, you could be paralyzed, you could be a vegetable. We don't know, we're messing with your brain."

Immediately a shunt was installed, a tube that pulls fluids off the brain and puts them in the stomach where the body can process them. And a date was set. I don't know how to explain the details, the trips, the information, the preparation

that took us from August to November. But I can tell you that after the diagnosis, my father never drove, never rode a jet ski, never worked again.

It's weird what you remember, the memories that stick out. For instance, I didn't have anyone to go with to my junior homecoming dance that fall. I wasn't going to go, and two of my friends, Carrie and Erica, made me drive to Madison and get an outfit. I remember that Dad came along. He couldn't drive anymore, but he hadn't had the big surgery yet. He rode in the passenger seat, and I drove, the girls in the back. We picked out pleather pants and a pleather tube top, the one Britney Spears wore, but mine was neon blue. I vividly remember that drive, in my brown Chevy Oldsmobile Royal. That car was significant because it was my main means of transportation, and I was my sister's main means of transportation.

Months later, after the surgery, after I had fallen in love, it was in that car that my sister accused me of being a slut. She had figured out that I had let Josh touch my breasts.

I remember that accusation.

As a family, you are often each other's targets of accusation.

And that's ok.

When I did go to homecoming, I didn't go out to eat with my friends, I went with my parents. We went to Damon's where we were surrounded by tables of eight, all in formal dresses, staring at the odd family; me in pleather, the three of us eating shrimp and steak, all enjoying it like it might be the last time we got to eat out together. You get really good at enjoying those moments, at knowing you should be conscious, fully aware, so that if it is the last, you will remember it. Even years later, after he died, that has stayed with me. Every time I hug my mother goodbye, I know it may be the last. Each time I visit my best friend Natalie, I take in her smell extra deep, just in case I never get to again.

"Sherrie Orcholski" <polocks@hotmail.com>

11/22/99 05:11PM

Although much of our "awakening" time is devoted to medicine, therapy, eating, and talking, we still enjoy special moments. When I read different E-mails to him or open the mail with him is always a highlight. Right after breakfast last Friday morning, when he was still on oxygen, a creative thinking nurse turned his large chair to the window and

sunny view of downtown Rochester. I, too, joined him for his last hour up that morning by turning my big recliner chair the same way. As we held hands, closed our eyes, felt the sun/warmth on our faces, and heard the rhythm of the oxygen mist, I could ALMOST imagine we were on the beach in St. Lucia as we drifted off to sleep! What a delightful hour that was in the mist of all the emotions, chaos, and commotion...

It's amazing that the distance between my mother and father at the hospital and us at home brought us so close together. My mother never left my father's side. Never. In the eight months where they practically lived at the hospital, she never came home by herself. Never. I think people assume that my sister and I felt slighted or distanced by this decision, but it was so natural. That's where she needed to be. Because she was in the right place, there was no gap, but rather an even stronger bond between all four of us.

There is a large amount of pride that we all had for each and every decision that we made. We were always honest, always true to ourselves. Regret becomes obvious as something you don't want. They had moved the big surgery so that it would not interfere with my sister's freshman homecoming. There had been complications with the prep in the weeks leading up, and that also affected the date. It ended up being Nov. 5th. I, as a junior, had finally made the school fall play. Our performances were Nov 4th, 5th, and 6th. We had been rehearsing for weeks. I was a lead, I didn't have an understudy, and my father would be operated on three hours away.

What do you do?

Do you drop out of the play?

Do you go, just because you should?

Would my presence at this hospital, helpless in a waiting room, make any difference?

If he died, would I regret not being there?

Not holding my mother as she felt the loss?

I remember Dad and I talking about it. He was only worried about me. "I won't know whether you're there or not!" When I knew he didn't care, I knew the only place to be was on stage. Why stop my life to be there in case his stopped? I remember the night of the surgery, I walked into the green room, and there, where

I always put on my make-up, was a vase of big beautiful flowers. Nothing kept us from each other. When I was young, and ready to be in love, but awkward and ugly, the only boy that would dance with me was my father. Middle school was marked by the intonations of Whitney Houston, “I Will Always Love You.” Dad and I would dance to it at weddings, me wondering if he would be the only man that would ever dance with me, him knowing that he was just filling time till I finally grew up. That night, when I saw the flowers, I played that song. My friend Dane, who played my husband in the show, danced with me. He silently let me cry on his shoulder and I took, not a moment of silence, but a moment of music, to be with my family.

I had told my family not to call, though Dad would be out of surgery by the time I had intermission, I just didn’t know if I could finish the show if he had died. But I knew. I don’t know how, I just knew he was ok. I called from the green room (how we managed before cell phones!), and I remember my mother’s voice, the shock that I had called. But I told her I knew. I knew it was ok. And I was right, he didn’t die that night. And when I finally got up to the hospital, we played oldies for him in his ICU room. Even in your sleep, you can still enjoy rock and roll.

There wasn’t a moment that he magically woke up. Each moment that something happened was magical. One time, he was mildly conscious, but not very communicative—still in ICU. Me, Mom, and my aunt Pam were feeding Dad breakfast. And we were just jabbering away. (When you’re half-conscious, you often get left out of the conversation.) We were talking on and on and started talking about children’s books—what were those children’s books we loved so much?

The little critter books. . . “Me too” “Me and my Grandma” etc.

None of us could remember the author.

And a grunt comes from the bed.

We continue jabbering. . . what was his name?

The grunt gets louder,

What? What, Dad?

“Mercer Mayer.”

We were stunned. I’m not sure he could have named everything he was eating at that moment, but somehow his brain still held this author of books we hadn’t

read in ten years. When you tell someone that your father was diagnosed with a malignant brain tumor that no one has ever had before, all they hear is tragedy. It is these moments they are not able to see.

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11/22/99 05:11PM

Appetite continues to be good. He's usually hungry when he wakes and never complains about what is fed to him. He does make mention quite often about a particular friend's sugar cookies, though! He just can't understand why he can't have them all the time as we try to balance the diabetes between "real food" and the steroids given (which automatically elevate the blood sugars)!. . . He brightened at each visit this weekend from everyone and LOVED having "his girls" here! It was wonderful, even if he's only awake about 6 hrs a day! Both of them took charge of feeding him a particular meal.....It melts your heart to watch.....

Feeding Dad was a coveted event. We all vied for the honor to feed him. And we all fed him the way we would want to eat. I remember questioning Mom as she put very little milk on his cereal. "That's the way he likes it" she replied. "No way! No one would like cereal with that little milk on it." I like mine floating. I still have no idea which Dad preferred, but he ate it both ways. He didn't care, and that in itself is so telling.

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He is becoming more aware of his capabilities (or in many cases, lack of). It is discouraging in many respects to him, but encouraging when the PT sessions take place. Today, with much effort and some help, Arch was able to sit on the side of the bed again. Once up, he could sit there over 5 minutes without help. In both sessions, he tried "stand".....Although just a few seconds in the morning, with help in the afternoon he actually took 3 sliding steps! It's just going to be extremely lengthy.....Too early to assess, even.....

"Sherrie Orcholski" <polocks@hotmail.com> 11/26/99 10:15AM

When he's awake, he's learning more about what is a disability or what he can't seem to do.....

We got to spend Christmas together. I don't remember what our gifts were, I don't remember specific moments. I just see from August until the next June as a calendar and the days are shaded in two different colors, one for when Mom and Dad were at the hospital, and one for when they were at home. And Christmas, at least for a few days, was the home color. A month or two later, they were home for a few weeks, and Dad got real sick, a reaction to his shunt. Mom and I drove a half hour into Madison to the only open Walgreens to get medicine. We didn't know if he was going to be ok. Mom was a wreck, but strong as always. And I remember vividly thinking, "This is your life now. You need to get used to this. You need to accept this."

After the surgery, Dad lost partial vision in both eyes and they didn't track together – devastating for someone who was used to better than 20/20 vision. But we had him. He was here. But he couldn't see his puzzles, he couldn't write well, he was slow. He was going crazy just existing, feeling helpless. While waiting for dinner one night, I brought up the Magna Doodle and told him to draw me a picture: "It'll be good for you." He looked at me like I had to be kidding. He picked up the Magna Doodle, and took the magnet that looks like an O, and marking the board repeatedly, sang, "O, O, it's magic, you know. . . never believe it's not soo."

Once, years later, I came home from college to visit. The few things Dad could do, when he was feeling ok, were laundry, cleaning the house, and cooking. Often Dad would just opt to sit and watch TV all day. On this day, the house was a mess when I came home, and I yelled at him. One simple thing, and he couldn't even do that for Mom? Sometimes we take out our feelings on each other, and that has to be ok. That night when I came home, the house was clean, and he had baked me a white cake with white icing—me and Dad's favorite. He had scrawled a note, apologizing for the house. He apologized, because I was a careless yelling brat. He ended the note by saying, "P.S I made you a white coke (spelled wrong.)" I still have that note.

Time is such a fascinating thing. These moments I've related are so vivid, and they are only a small part of what I remember. I could go on and on about moments, both good and bad. And yet, there are so many things I have forgotten, so many

moments that were spent waiting, crying, sleeping, so many moments lost. I can try and tell you our story by these signposts; I can try and explain what happened in this passage of time, how it moved, how I felt. But I reread my mother's emails, and I hear people recount stories from this time and the next five years and I often don't remember all of the moments. We point to that diagnosis. That was the Monday everything changed. It starts there, and the story continues until he passed away in our basement on a Saturday morning. But I can't show you all the hugs. I can't illustrate the moments we knew were stolen, we knew we were lucky to get. I can't paint the night he seized, where I saw true ugliness, I saw uncontrolled evil take over his body, the fluid leaking onto his brain. I can't describe what I felt the night, years later, that he wasn't strong enough to get from the floor to the chair and we weren't strong enough to lift him. We had to call his old fire-fighter friends and they lifted my half-naked father into a bed he would never leave again, the bed he would pass in only a few weeks later. The memories, the moments from diagnosis to death are innumerable.

I often explain to people that I lost my father twice. Once was obviously when he died five years after diagnosis. We knew if the cancer ever came back, we had exhausted all options. And one day, it did. But so many parts of him were taken away while he was still alive, which created its own kind of mourning. This process implies loss, creates absence. Void. Yet, I don't think it stops there. I never felt empty; I never felt a lasting hole of absence. Just how air takes the shape and fills up any container, our emotions fill up and take the shape of our lives, no matter what is altered or cut out. There was a learning, a filling, a movement to this time that cannot be described as a lack.

My sister and I, in a car, on the phone, or in bed, have discussed how these events have made us who we are. What terrible people we would be without these lessons. We would be moving without knowing, looking without seeing, allowing the people and moments to pass by us. We know. Because of Dad, because of these five years. Even now. We know.

Megan Orcholski