When the People You Love

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*“When the people you love are diagnosed with a life threatening disease, you start to question how your actions affect the people around you.”*

And then it hits you. Your life is no longer the same normal routine. Here I am, standing at my wife’s funeral watching as my daughter cries at the foot of her mother’s coffin. Her big brown eyes filled with tears. The sound of cries echo throughout the room as family and friends pay their respects.

We don’t have much family around here. Both my parents and my wife’s parents passed. Now all that is left is my daughter, Madelyn Nadella. “Daddy, why did this have to happen to our mommy?” she asks. Unable to answer, I stumble to find something, anything that will soothe my little girl’s heart.

“It’s science baby. Just the luck of the draw. Someone else from her family must have had it before her,” I finally say. What kind of answer was that! How was that supposed to soothe a ten year old girl?

What makes things worse is I think I could have done more to help my wife. I am studying this particular disease, Arrhythmogenic Right Ventricular Dysplasia, in chimpanzees at the University of California San Diego. Arrhythmogenic Right Ventricular Dysplasia (ARVD) causes a deformation in the heart which leads to heart failure. And I think we found a cure.

I know how rare this disease is and how successful we have been to prevent sudden cardiac arrest but it wasn’t as successful in this case. My wife was diagnosed with this disease on December 17, 2014 and died only two months and one day later on February 18, 2015. It was a big surprise to everyone. Her cardiologist said she would have been able to prevent her heart from shutting down by implanting an ICD (implantable cardioverter defibrillator), but there just wasn’t enough time. There never is enough time.

Well, here I am at my wife’s funeral. “Maia Nadella,” it starts. I look to my left as Madelyn hides her face in her mother’s big, red scarf. I never was the comforting type. Awkwardly hugging my daughter in my arms as we cry together. Holding her as tight as I can, never letting her go. Maybe too hard, she wiggles her way out, dress flowing in the wind, as she reaches to grasp my leg. Madelyn always hugs my leg. Her support beam at just the right height. It’s only a matter of a couple of years before she will be too tall to hug my leg for balance.

“Daddy can we play the world game today?”

We used to always lay on the floor in her room, creating worlds that only we would understand. “And then she can fly to school but when she flies she is swimming. But in the air!” Madelyn would exclaim.

“And then she can run to the other side of the world. Like by running on water. Like Dash from the Incredibles!” I would add.

“Daddy, that’s not creative enough,” Madelyn would criticize. “What if she could move the water to make water walls and she ran on the ocean floor from one continent to another!”

“I would love to play the world game with you later today,” I finally responds.

Madelyn starts, “A world without diseases.”

I don’t even know where to start. Before it was always about super powers. My daughter is growing up. Getting more and more sophisticated. “And you can never get hurt,” I add.

Madelyn starts crying. I know she is crying because of her mother but…

It has been a year since Maia died. Things are starting to get easier. Madelyn doesn’t cry everyday and I am doing a lot of research at the University with Professor Roberts. We have played the world game a couple more times but now Madelyn likes to make up worlds that are more realistic. “I am a really, really good volleyball player. I can jump higher than the net.” “I am so smart, it only takes me two minutes to do a two hour assignment. And now that I saved all this time, I can do whatever I want.”

Madelyn came running into my room crying, tears running down her face. Rosy cheeks with short, fast breaths trying to grasp any bit of air she could. Worried, I take her to the emergency room.

“Madelyn has Arrhythmogenic Right Ventricular Dysplasia,” says the cardiologist.

I can’t contain myself. Why us? We knew it was a possibility but not at such a young age. She is the only thing I have left. I can't bare to see her face when he tells her the results of the test.

You can only imagine how frightening it would be for a little girl to hear that she has the same disease that took her mom's life only a year ago. Madelyn sits there, as still as could be when the doctor and I walk into her room. As she looks up to see my face, she knows what is about to be presented. Sobs escaping her mouth as she listens for the confirmation.

Because Madelyn is only ten years old, she doesn’t fit the profile for the medication the doctors would want to prescribe her with. Her body might not be able to handle the medication. Doctors are looking to see if different dosages of the medication will still be enough of the medication to help prevent cardiac arrest while her body takes in the nutrients. But I have an idea of my own.

"Professor Roberts, I know we haven't finished our research but I was wondering if you could take a look at one more case."

"ARVD, 10 years old, female, signs of increasing heart rates, fast breathing. Where is this chimpanzee?" she asks.

"That's the thing, this is my daughter. She was recently diagnosed and I want to know if you would help me. This is the only thing I have left to live for. I will do anything to help my daughter. Please, would you just consider it?"

"No, it is just too risky. We haven't even tested it on humans yet, let alone a little girl. She will do just fine on medication and worst case scenario, a transplant. Plus human testing is illegal. I am sorry Marcus, but there is nothing I can do to help your daughter."

What does she mean? How is saving my daughter’s life “too risky?” It may be risky for my daughter but not for Professor Roberts! There has to be a way to get my daughter this procedure. She needs a new heart.

Day after day I talk to Professor Roberts. Trying to get her to do the procedure. But still it is “too risky.” How is it “too risky?”

Madelyn comes running into my study, “Daddy, daddy it’s getting hard to breathe.” Her face is red, she has a fever, and is sweating like crazy. Her condition must be getting worse. I take her to the emergency room, with one thought. She is going to leave me. I will be all alone.

“The muscle in her heart is gradually being replaced with fibrous and fatty tissue. She is going to need an ICD, implantable cardioverter defibrillator. It will help regulate her heart rate.” What does he mean she needs an ICD? She needs a new heart! Do they not understand, the muscle strands are breaking down.

“We don’t want it,” I say and walk out of the hospital.

On the way home we stop at UCSD to talk to Professor Roberts. “Please would you just try. What could go wrong? She can’t regrow a heart? It’s not like it will kill her.”

“No, it is just too risky,” Professor Roberts states with a monotone voice. Showing no emotion to my daughter and her life threatening disease.

I head to the storage room in the back of the lab. Grab two test tubes, a sample of the antibodies and a scalpel knife.

It has been a month after I completed the initial procedure. Implanting cells into her body that will replace her heart with a new functioning heart. Madelyn is doing good. She hasn’t had any irregular heart beat patterns and can almost go back to her regular routine.

“Daddy can we play volleyball?”

We haven’t played volleyball since before she was diagnosed with ARVD. She always ran out of breath fast and we could never get a rally going. “I would love to play volleyball with you, but are you sure you will be fine?”

“Of course I will. I mean I have a new heart don’t I?”

Bump, set, spike, dig. Bump, set, spike, dig. We had some really good rallies, until Madelyn got upset. “You are hitting too hard! I am not good enough yet!” Anger and frustration heating up inside of her. She threw the ball and stormed off.

Lately Madelyn has been having some anger management issues. I plan on taking her to a counselor when I can finish the final part of the procedure.

Running into the lab to grab the finishing pieces for the final part of the procedure, I must be sure to stay out of sight of Professor Roberts. I still don’t understand why she didn’t want to support me in this. All it can do is help. What is “too risky” for her?

“Marcus Nadella!” Professor Roberts calls out. I stop and turn around, unsure of what to expect. She must have been waiting for me. “I know what you are doing and it needs to stop now.”

“What, trying to finish my research?”

“I am not in the mood to argue with you, please just leave now. I know this isn’t for research purposes.”

“I am just doing my work. Whatever it takes for me to finish this. My daughter needs this.”

“Your daughter does not need this. She doesn’t need to be a test subject. This isn’t complete and should not have been done in the first place.”

“What could go wrong? She doesn’t live? She isn’t going to live anyway!”

“That is not a decision for you to make.”

“Don’t tell me what I can and cannot do. I will do whatever it takes to save my daughter! She is the only thing I have left and I am not going to let you get in the way of things!” Frustrated and angry I continue to gather the supplies I need.

Out of the corner of my eye I see Professor Roberts grab the fire extinguisher. Worried that I would not be able to handle the blow, I reach for the first thing I see. The scalpel knife.

Everything is a blur. Things being thrown, glass breaking. Then suddenly, I see Madelyn appear from behind the door where she was waiting for me. As she enters the lab, I see anger engulf her entire body. She rushes toward Professor Roberts with no hesitation. “Madelyn STOP!” I scream. She grabs a beaker from the edge of the table and attacks the back of Professor Roberts’ neck. Glass shattering and flying across the room. Viciously slicing Professor Roberts’ neck until she finally collapses.

I look up to see Madelyn’s face. She looks relieved that I am not being attacked but terrified. My daughter just killed someone. My perfect little angel just killed someone. What are we going to do? Madelyn stares at the blood. Her eyes never moving away.

“Daddy, I am sorry. I don’t know what I was thinking. I just… I just… I don’t know what is wrong with me.“

Unable to comprehend the situation, I turn away. Take a few breaths then kneel down to where Professor layed cold. No pulse. She is dead.

It has been a stressful month, hiding the body and watching over Madelyn. Madelyn is really starting to scare me. Her body is transforming. Growing hair, getting angrier, she almost looks and acts like a real chimpanzee at this point. For now, I am just going to keep her locked up in the basement at home, but I can’t keep her there forever. People are going to start questioning me. People are already starting to question me. I need to find a cure.

In the chimpanzees I never saw any irregular behavior. Why is she acting like a chimpanzee?

I test to see if it had to do with the test samples I used but they all contained the same substance. Maybe it was the amount I implanted? But I did the same ratio.

Day after day, month after month, I devote my entire time to my daughter. Taking care of her and trying to find a cure. Nothing was working. Madelyn’s condition is getting worse. She attacks me everytime I enter the room. I don’t think I can handle it anymore knowing that she has the power to kill someone. I don’t know what to do next. Homicide detectives are onto me. I don’t think I can keep this a secret any longer. Madelyn isn’t even my daughter anymore. She is more of a test subject.

Should I turn us in? We need help.

I got it. I didn’t notice anything irregular because chimpanzees already act and look this way. The DNA that I used must have been too similar to that of a human that her body started to recognize the same proteins. Those proteins had characteristics of the chimpanzee that Madelyn adopted.

I hear scratching behind the basement door. She must be trying to get out. I need to secure the basement. I am almost done with the chimpanzee cure. Hours on end, trying to work as fast as I can. I am almost done. Only a few more tests.

Madelyn’s condition is getting so bad, I can’t even feed her. It has been a few days since I last saw Madelyn. I can’t run from it anymore. Maybe I should have gotten the ICD implanted? Will Madelyn grow to be taller than her support beam?

“Ccrrrrrrkkrrrrrrr! Ccrrkkrrrr!” Then suddenly, it stops. I wish I knew what was going on behind the door. I grasp the handle in anticipation of a chimpanzee waiting patiently to attack. Pearing through the slight opening, I see Madelyn on the ground in the center of the room. It is dark and dingy except for the little amount of light making its way in from behind me. Weirdly, Madelyn doesn’t move, not even a flinch. Cautiously walking towards Madelyn, I survey the room. Scratch marks covering every wall. Boxes scattered throughout the room. Everything was destroyed. Except one thing, the scrapbook that Maia made for Madelyn when she was born. Now I am looking down at Madelyn and all my memories of her flashes before my eyes.

I have nothing left to live for. When the people you love are diagnosed with a life threatening disease, you start to question how you actions affect the people around you. Would she still be alive if I got to her sooner? Would she still be alive if I hadn’t even done this procedure in the first place? It is all my fault. I should have just gotten the ICD implanted. How can I be so ignorant as to let the two things that matter the most to me ever slip away?

I raised the pistol to my temple, and counted to three. One, two, three. I felt all of the colors of the universe at once.