

As a society, we focus on “health” merely from a physical standpoint. There is an emotional toll that is not acknowledged alongside disease. My work was created to access my own perspective on my father’s disease. Prior to undertaking this project I hadn’t realized that *I* could uncover my side of the story. I explored a variety of questions: how can a disease affect a group of people? Where does someone, who witnesses sickness, fall into the system of disease? Do generational differences within a group affect people differently? This is personally important to me because my dad has Parkinson’s disease, so it is prevalent in my daily life, and I wanted to consider how this disease has affected me.

These four self portraits show varying levels of impact on me - someone who experiences, but is not diagnosed with, disease. I have never worked with oil paints so I think that struggle and bravery added to my piece. I have never talked about or created work based on Parkinson’s disease, so it pairs nicely with a medium that I have no experience with. By incorporating different styles, I created contrasts between each self-portrait in order to more deeply show the depths to which I have been affected by my father’s diagnosis. The one where I am bald is inspired by Francesco Clemente’s portraits, the one with the batteries on my head was inspired by Marlene Dumas, the one that is upside down is inspired by Georg Baselitz, and the one that has no intentional alteration is inspired by Jenny Saville.

The same red background unites the four portraits reflecting the idea that we are all in it together. To see myself with the things that my dad may be ashamed of, reassures the fact that there is no need to feel that shame, exemplifying the compassion that persists in my family. By pushing my own boundaries of using oil paint for the first time, investigating Parkinson’s and how it affects me, publishing my work, and remaining patient and persistent, I have discovered my capabilities. My weakest spots and hidden secrets don’t have to be considered disadvantages.

Billie W.

Symptoms of Being a Witness

Brooklyn, New York

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WRITER'S NOTE

I am creating this project to explore the inner workings of how a disease affects a group collectively. I am going to focus on the differences and connections between someone who is diagnosed with a disease, and someone who is a witness of disease. Both experiences affect a person and I want to unravel the contrasts within a family that experiences it. I am researching the effects of sickness on people who aren't diagnosed with those diseases. I want to explore aspects of experiencing a disease that isn't as commonly treated or discussed. I am highlighting the contrasts and differences in being affected by sickness. I will be exploring a variety of questions: How can a disease affect a group collectively? Where does someone, who witnesses sickness, fall into the system of disease? Do the generational differences within a group affect those people differently? How does it affect me differently? This is personally important to me because my dad has Parkinson's disease, so it is prevalent in my daily life.

INT. DOCTORS OFFICE - DAY

Billie is in her father's neurologist's office waiting room. It is a Thursday afternoon and she came from the subway, just a few blocks away. The lamp in the room reflects a blue light that begins to give her a headache. The chair she is sitting on rocks on its joints, screaming creaking noises. She starts to look at the clock just as the doctor enters from the hall and calls her in.

Doctor

Hi Billie. I'm Dr. Dumach.

Billie

Oh yea, hey.

Internal Monologue

She has a deep voice. She could probably be a singer.

Doctor

Thanks for coming all the way. I have asked to talk with you because I want to explain some stuff to you about your father.

Billie

Okay.

Doctor

Well as you know your dad has Parkinson's Disease. It's a progressive nervous system disorder where the neurons in the brain start to slow down and die. These neurons are the ones that control movement and physical ability.

Billie nods to reassure the doctor that she can keep going

Interior Monologue

What is this doctor saying? Does she expect me to understand what it means for a neuron to die? Why use a word like die? How many need to die before I see a difference in his ability? What is "progressive" about Parkinson's anyway? It seems pretty disruptive if you ask me but I'm not the doctor.

Doctor

Everyone is affected by it differently. Some people develop tremors. This basically means that their hands, legs, head, or vocal cords can develop involuntary

shaking. You may be familiar with stuttering? Because that is something that Parkinson's patients suffer from.

Billie sits up on her seat and lowers onto her hands

Interior Monologue

Tremors? Seriously? He won't even be able to control his fingers? Well, what about his books? It's who he is. All he has dreamed of. Working from nothing. Building it all up. Studying. Creating bedtime stories. My brother and I dreamed of his stories. Quite literally. And now, it couldn't wait. He started with hope. 3 books down and now you're telling me it will begin to slow. The unstoppable shakiness of his fingers demanding undivided attention. Prohibiting the stories. No more typing.

Doctor

Muscles may stiffen. This can cause difficulty in standing...

Billie raises her eyebrows as she begins to feel antsy and her toes curl up in her shoes

Interior Monologue

The concerts. The thrill of his life before. Taking away his ability to experience the things he loves about the world with the people he loves, a human right. All of the experiences a family waits to have. The kids are finally grown and we start to appreciate the museums, the traveling, the friends, the dinners, the beaches, the food, the conversations...All of the patience he had. Now we can't do it. At least not with bliss. What was the point of waiting and saving? Would he have planned the same if he knew it would never work out?

Doctor

Sleeping issues as well. Patients suffering from early awakenings, nightmares, and restless sleeping.

Billie

Okay well, that can be managed with melatonin and meditation.

Interior Monologue

Melatonin, a small 5 mg pill that aids humans to shut down from reality. That is the supplement that will help him

manage this? I want him to stay awake with me. To stay breathing with curiosity and vigor.

Doctor

Yes, that's good thinking. There are ways to manage these things. However, balancing may also be tricky.

Billie

Can that not be managed?

Doctor

Unfortunately, no cures have been discovered yet; however, there are procedures and medical treatments that prevent the symptoms from intensifying. There are walkers that are designed for Parkinson's patients. We can also help your family get handicapped stickers for parking. And at airports, you can skip lines when he's in a wheelchair.

The doctor smiles as if she's trying to sell a product she knows is useless

Billie looks at the doctor with her eyes wide open, as if she is saying "duh", signaling for the doctor to move on

Interior Monologue

A walker? Do you really think a walker is going to help? Are you trying to make this sound like an advantage? Yeah okay, parking a few cars closer and getting through customs faster sounds *SO* appealing. What about when he is treated differently? These "advantages" will never equal the difficulty of their cause. Whether there are special treatments we can get or not, I think he's going to want to be able to take care of himself. When he tries to walk on his own, he is going to take the risk of falling. But that is not the issue. The issue is when he attempts to live independently, as the man he is and has been all his life, but fails, and falls onto the sidewalk. Then, people will come over. Is there any sign he can put on his back to warn the strangers away? What about that? People will stare and ask if he's okay, but that won't help. Do you have anything that can enable him some space to find his balance again? To allow him to focus for a second without a bunch of randos coming over. These people that don't treat us normally. They are admitting themselves as heroes without actually helping in any way.

Doctor

What do you think of that? Huh?

Billie

Oh yea, I've always hated waiting in those lines

Billie laughs politely

Doctor

Don't we all. Well, there are a few others. He may experience confusion in the evening hours, like difficulty in understanding or thinking.

Billie has a blank face. She is numb to these facts by now. She is confused about how to react in front of the doctor

Interior Monologue

So do I need to take on a new role in the family? Will I have to address things I am not suited for? Does this make me guilty? For not being able to bring myself to help him clean the broken glass he just dropped, or the blood on the floor. Making me helpless in a scenario where I could have helped.

Doctor

Similar to the stuttering aspect, there can also be a difficulty in speaking. You may hear softer speech than usual.

Billie clears her throat

Interior Monologue

Than usual? Will anything be normal?

Doctor

And remember that with all of this, nothing is guaranteed. Most people only experience a portion of these effects. There is no certainty right now. I have called you in to calmly warn you of potential surprises. It's also important to remember that even though it will directly affect your father, you and your family will be involved. And mental health is a major thing to be aware of. This unfortunate truth can put an emotional toll on a family. Mood, depression, and anxiety have the greatest impacts on health status, even more than the impairments associated with Parkinson's disease.

Billie

How does it affect me directly?

Doctor

Well, this is a question that only you can answer. What do you think?

Billie

I would guess that a disease will make things more difficult. I mean in general when anyone gets in a mood in my family, there is a butterfly effect that takes place. It's all pretty contagious. Will the ways that he feels become contagious?

Doctor

When surrounded by sickness, the emotions that people are feeling can spread but the disease itself is not contagious. But with patience, you will learn to work with it and live through all of it. After all, you have that responsibility.

Interior Monologue

Do I? I guess partly because I am a part of my family. But I shouldn't have to constantly be challenging myself to take on a role that I don't feel fit to play. Aren't I going to be involved enough? In my family when someone gets upset, it's usually just out of the mood they are in. However, when surrounded by sickness, there is no escaping that reality. How do I learn to be okay with that?

Doctor

You will need to learn to help everyone. You should be thankful to be as healthy as you are.

Billie

Yes, of course. I'm truly lucky.

Billie looks at the floor of the wall to the left of the doctor, in hopes that the piles of dust can save her in some way

Interior Monologue

Stop telling me how to feel! Is that the only reason I'm here right now? To be hired. To lose the privilege of solely being a daughter? Or is that irrational? I mean I am the one with the choice to leave all the blurriness and shame that my dad probably feels. I am not tripping as I walk. I don't face the symptoms of being diagnosed with it. But what about my mental health? You're clearly

leaving that out of your definition of "health." You don't have the right to tell me what I am. I'm going to have to learn to be okay with my dad not being able to walk with me everywhere. But you're clearly not helping with that right now.

Doctor

Well, that's good because this is extremely unfair to your father. So I advise you to remind yourself of how lucky you are.

Interior Monologue

Lucky?! Other kids my age don't have to worry about this. I get that everyone has stuff going on but my situation certainly doesn't feel equal to theirs.

Burning up.

My cheeks.

My throat is swelling.

Why is this hitting? As if I am being shot down directly by the endless amounts of dead cells that will remind me of this. Everyday. Why do they have to involve me? I am not the one with Parkinson's. Why my dad?

Doctor

Be easy on yourself too. As a society, we only ever focus on the diagnostic. There is also an emotional aspect that is rarely treated in the same way.

Interior Monologue

She's right. Do I even have the right to make this all about me? Truthfully, I should be a little selfless. It could be way worse. But she is touching on the aspects of life that aren't treated by doctors. How are families expected to cope with the emotional toll that is not treated along with the disease? What is she even doing here? Especially if she's not planning to help me!

Billie

Yeah, I guess. I mean...

Billie swallows, trying to push away the lump in her throat, and looks up at the ceiling with her cheeks sucked and her jaw flexed into an underbite

Interior Monologue

Won't I get jealous? Upset at my friends when their lives are working out.

It is hard to be happy for someone that doesn't have much going wrong for them. Is this disease the root of all that I will feel pain and jealousy towards?

Billie

I don't know. I mean I barely even address it at home. I excuse my situation because I know it's not directed towards me...

Doctor

And I think that that in itself is something to tackle. Because you avoid the struggles, your frustrations come out in different ways.

Billie

Yeah, sometimes I worry that if my dad wasn't sick, I wouldn't have an excuse for the reasons I get upset.

Someone knocks on the doctor's door from the hallway

Doctor

That is not a good way to approach this. Your dad has a disease and you are affected by it. You will never be able to see what it would be like otherwise. You are being raised in this environment and you are probably developing your own symptoms of being a witness of disease.

Billie

I've never really thought of that.

Interior Monologue

I'm pretty numb to the fact that I have a lot of anxiety, I get closed off about my personal life, I have a lot of confusion on how I'm supposed to feel. There is a weakness in not being able to deal with it. I'm not aware of the things that devastate me.

Billie

It's not a very comfortable topic.

Someone knocks on the door again

Doctor

ONE SECOND! Exactly, and imagine how your dad must feel. Body image and self-esteem erode when people are labeled as "disabled".

Billie

Wow, that's just unfair.

Interior Monologue

To think that the one who has to struggle involuntarily, has to feel ashamed by their struggle. And the rest of us don't. We aren't ashamed of our individual selves. But he may be and he probably also feels ashamed for us. We don't have to deal with that. And with that, I don't know how to assure him otherwise.

Doctor

Yes. I am sorry that this is the case.

Billie

Sorry for me?

Doctor

Yes for you. This will obviously affect you, and I'm sorry about that.

Interior Monologue

No one has ever apologized to me for this reason. Even though I don't have Parkinson's, it hits me too and people fail to realize that.

Someone knocks on the door again

The doctor hands her business card to Billie

Doctor

COMING! Alright well here is my number so text me anytime with questions or concerns. I have another appointment right now.

Billie

Oh yes, of course.

Interior Monologue

Oh yes, of course. I forgot I was just another patient. She doesn't have to worry about me or my family in her actual life. I doubt she really cares about the rest of us. The ones that have no reason to "need" help from a doctor. The vain ones that don't have any real problems that need fixing. After all, we don't need doctor visits, surgeries, and endless amounts of medication.

Is this what she was thinking? Why did she even apologize to me?