

Contents

Fatima Muhammed-Ighile 20190605	1
Opening 01:37	1
Don't Know What They Don't Know 02:50	2
She's a Superwoman 05:20	2
Fragile Egos-> Better Advocate for Myself 09:45	4
Meanest Mom 11:15	4
Let Them Fall 13:49.....	5
I'm turning into my mom 16:27	5
I'm not drug-seeking, I'm in pain 20:32	7
It takes a toll on the whole family 25:15.....	8
Working with a chronic illness 28:55	9
Turnaround: You taught me to accept myself 30:23	9
Being a boss of a person 33:47	10

Fatima Muhammed-Ighile 20190605

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Opening 01:37

In earlier episodes we heard from Sara Lorraine in high school and Morgan in college. This episode concludes the conversations with Fatima Muhammed-Ighile, a mother with two young children, and her mother, Esosa, navigating Sickle Cell Disease. These conversations have been different as Fatima and I are friends. We are familiar with each other's families. We have shared some of life's milestones. In this episode, Fatima finds that she's turning into her mother and describes her experiences as a young mother of color seeking pain relief from a sickle cell crisis as the opiate crisis heats up. Hang on.

Health Hats: Esosa and Fatima it is just wonderful that you've joined me. I thank you so much. What I want to do is ask a few questions of you. I'm going to start with you Esosa, okay?

Esosa: Okay.

Don't Know What They Don't Know 02:50

Health Hats: You've managed five kids, two of them with sickle cell and so now that they're older and you're older and maybe wiser who knows. What would you do differently now that you've had all this experience?

Esosa: I wouldn't change a thing because I know that God has a plan for every one of us and it comes to pass so I wouldn't change anything, but I would have preferred if none of my kids had any disease. We don't get to choose.

Health Hats: But I guess I'm thinking about all the challenges that you had with the doctors and the hospital and the schools. Is there something about that, that you wish different? Or now that you know what you know, you might have approached differently any of those challenges?

Esosa: Yes, I was able to make the school system aware of the challenges we were having because I have the supportive team of hematologists and pediatricians and all of them. But at the same time, we think that would have helped us along the way better would have been more awareness.

Health Hats: Meaning of that the schools and the doctors would have known more about Sickle Cell early on?

Esosa: Yes, that would have been very helpful. But instead of them telling me what to do about the disease, I ended up doing my own research and providing them information.

Health Hats: So, you were teaching them?

Esosa: Oh, yes, not that I know much. I don't know much, but I was doing research and providing these schools and even my pediatrician was very honest by telling me that he didn't know too much about the disease, but they were willing to work with me.

Health Hats: Okay? Well, so that's good. I think the hardest thing is when people don't know that they don't know.

Esosa: Yes.

She's a Superwoman 05:20

Health Hats: when people say, "okay, well, I don't know, and then they're willing to learn that is a start." Yeah. Okay. Fatima, a question for you, so, you know when you and I work together, and we were

talking about our respective chronic challenges, illness challenges. One of the things that you were pretty strong about was self-care, and you would say to me, "What are you doing to take care of yourself? How are you managing the stress? Are you spending enough time with your grandkids? You would be talking to me about that.

Fatima: I did that? I'm sorry.

Health Hats: No. You did. It was great. I felt like this is something that we were able to share: How do we take care of ourselves? When did you first realize that your mother needed to take care of herself? Here she was taking care of the five of you and spending all this time as you said when you were 10, you just knew everything. But there was a moment where you were growing up, and you realize oh, it wasn't just about you. It was about the whole family, and it was about your mother. How did that happen that you started, thinking about what she was going through?

Fatima: Huh, if I'm going to be honest, it took a long time. It's not until I went to college and I realized while life is hard. I was 10 hours away, driving distance in a completely different state. The first time I was without my parents, my family. We have a huge extended family. So, I didn't know anybody. I was just there by myself. Nobody there to say, "Stay hydrated or don't stay up late." I would pull all-nighters and eat like crap like the other students and end up in the hospital. So, it took a couple of times of that to realize, my God. I can't do that. I can't stay up all night. I have to stay hydrated. I still ate like crap, but I had to at least squeeze one nutritious meal in there. I had to take care of myself, mentally and physically. I realized what a huge role my mom played. I was just like, "how did she do this?" That's when I realized she's a person and just saw her outside of like my mom. She is my on-call pro bono PA, nurse practitioner, my chef. All this unpaid work that she did just purely out of love. I was like, "oh my gosh." I remember calling my mom. I didn't know detergent was this expensive and she's said, "yeah, that's your budget. Make it work." I was like, "but you don't understand." I was telling her that she didn't understand how expensive life was. I think that was the first time I realized, wow, she's a person. Then whenever I come home, I just appreciated her way more and then again, when I gave birth to my first child. Not only she a great person, but she's also superwoman. She's amazing. She's not real. So that's when a lot of things clicked, and I realized how much I loved my daughter and my child. I was like, oh my God, it must have really killed her heart to watch me being in pain and yet she still went out of her way to make me try to be independent and put away her mommy hat. Not her mommy hat, but she had to look at the future. She put on the hat that I needed at that moment to become the person that I needed to be to make it in the world. So instead of just kissing me and cuddly me like I would have liked at that moment. I'm like she would have wanted to do. She really wanted me to be something, to be independent. I think at that moment is when I had a whole another realization that really just it was a deeper realization that when I was just in college trying to take care of myself.

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Fragile Egos-> Better Advocate for Myself 09:45

It's funny because she said that the thing, she would have changed is having a better-informed team. I feel like that's the thing that shaped me. If I grew up in a community like the University of Pittsburgh Healthcare System or Gainesville in Florida, places that have huge structures built for sickle cell patients. Where the hematologists are Sickle Cell specialists and the nurses are nurse practitioners specializing in hematology for sickle cell patients. Everybody from the phlebotomist is well-aware and well-informed about Sickle Cell. I would have been completely complacent - not as good as an advocate. It would have taken me a much longer time to understand that not everybody knows what you need. Or cares what you need. You're going to have to figure this out. Educate. You're going to have to find ways to explain to doctors that they don't know everything. Because you know that comes with really fragile egos. I don't know what they feed them in medical school that causes some people to have such fragile egos. I feel like that has it helped me learn how to navigate the healthcare system as an advocate for myself. And so it's funny that that's what she picked is what you would change and I feel like that's the thing that helped me seeing her advocate for me and going above and beyond and she didn't know something learns to learn about it. Ask questions figure it out and then educate. I think that was transformative.

Meanest Mom 11:15

Health Hats: Wow. That's so interesting. You know, it's ironic but makes sense. Esosa, Fatima is as independent-minded, and I have a feeling as stubborn as you are. The apple didn't fall far from the tree. As she got older, you were trying to set things up so that she was controlling and managing her Sickle Cell challenges herself. What kind of transition did you see in Fatima as she was growing up and she was a normal teenager? "Mom, you're not so smart." How did you see her develop in terms of her taking charge and being more independent?

Esosa: Yeah, I think I came off at the beginning as the meanest mom in the world like she was alluding to. Because all I wanted is when I'm dead that they should be able to stand on their own two feet so, in the process of doing all of that, I remember her fighting me to go to the University of Pittsburgh and I can say no no, no, no. No, that's too far from home. That's too far from home. But I thought she was fighting me. I realized that oh Lord, she's like me. I came thousands of miles from my mom. Now she's going away. I was taking confidence in the fact that they were involved. Fatima was very involved in knowing what was going on with her body. And like she said rather than cuddle them, I used to say, "okay, you going to take your medication. Your day's going to go on." Knowing fully well that in my heart of hearts, all I wanted to do is hold her and say, "the pain is going to go away." But that was not going to help when I'm not there. I knew I couldn't have been there 24/7 all the days of her life. So, she did really

well. It was tough for Mom. You know, I just crawl and cry and say, "why me?" But it wasn't in the books for them. Yeah.

Health Hats: Wow.

Let Them Fall 13:49

Fatima: She dealt with a lot of attitude. A lot of, "you're not my doctor. You don't know. It's my body. I know what my body looks like. Okay. Oh, yeah, I know my body." "Are you sure you should dress a bit warmer or you look a little tired maybe you should go to sleep?" And I said, "I know my body." When you're 16, you know every single thing about the world. No one can tell you. So that was difficult. But I think our pediatrician, Dr. Usmani helped you learn to set boundaries. I remember her telling me, mommy remember, "you're just going to have to let them fall."

Esosa: She used to say, "They don't want to take it. Let them get sick. I'll see you on the seventh floor." She just didn't want to take it.

Health Hats: You didn't want to take it?

Fatima: There was a time where I was just so stubborn, "I don't want to take it." I believed that I feel better now. I'm okay, and I don't want to be different. Even though nobody seeing you take the medication. It makes no logical sense. Who am I protesting against? I'm hurting myself? So my mom used to force us. We'd argue about it. Then she'll say, "okay stand here. I'm going to watch you take it." Then finally, after meeting for the millionth time with the hematologist, the hematologist said, "just leave her. Don't take it." I was like, "wait, what?" "Yeah, don't take it. It's your body. You know your body. You know your health, So whatever." I was like, " wait, what?" So then I didn't take it. I got sick. And then I was in the hospital. Usually when I go to the hospital, my dad, my dad is the big softie. He brings us Dunkin Donuts- lots of sweets. "Are you okay?" And my mom was just like, "oh you're here, okay. See you when you get out." That kind of tough love was made me realize how dumb that was. I sometimes think when you're that young, you want to fight with the wind if you could - just with the air. Whatever. And the mom's always a perfect target.

Health Hats: Fatima your kids are young, but your daughter is getting to the place now where she's... How old is your older daughter?

Fatima: She turned two in April

Health Hats: Two. That's young. I'm sure she's asserting herself. So, how do you how's that going?

I'm turning into my mom 16:27

Fatima: It's horrible. She's just like me, which is the worst part. My parents don't help. I can't complain to them because they love it. They love every moment of this. She's so similar to me, which is very

irritating. I'm like, "wow, God plays a good one on you sometimes." I'm working through it. The number one thing is I'm trying not to take it personally and self-talking my way through it because I don't want to discipline out of anger. When I get angry like that, I have to remind myself, "look, she's two, and she's testing the boundaries." I have to take a time out myself to breathe through it and come back. One thing is I stay home with my kids, and it's a huge sacrifice for our family for me to do that. I try to say yes. And I try to give her that freedom at times. Because I know when the times I need to say, "No," it needs to mean "No." And I don't ever want to go up to my kids and lose. I want them to know that if you're going toe to toe with Mom, you will lose. So with that in mind, I don't know how realistic that's going to be. But so far it's working with that in mind. I'm trying to. Be more of a yes if I can say yes, I will say yes. I'm trying to be that or if you go for a walk something as simple as like, okay, you lead the way we're all following Zuvada. She loves it. She thrives off of it. And I find that the tantrums are a lot less for the rest of the day. They want to feel because you're human beings. They want to feel control. They want to have some power. Yes. And so right now I can play the Mind Games and still win. But soon she's going to get better at those, too and then the mind games...

Health Hats: Well, you have a good example to follow. It sounds like your mom was pretty good at it.

Fatima: She did. I think she let me to the dismay of like our very authoritative, extended Nigerian family who just said no for the hell of it. She tried to be a yes Mom, and she would take us to cultural events out in the city and ride the train to Boston. It's funny now that we're older, I realized that my other cousins were super jealous of that. The fact that she said, "yes, go to Pittsburgh" and was "fine you're in God's hand. I trust you." It means so much to me today that it makes me want to build a daughter who's independent enough and trusts herself enough to try in the world and trust that you can do it and that God will keep you safe. And I hope that my prayers for her always keep her safe and that's all you can hope for and pray for it. It's harder that way, though. I wish I were a cuddly parent. I feel like it's much easier in some ways.

Health Hats: Yeah. It's probably easier in the moment. We would try to come up with choices that were both okay with us. Then they would get the opportunity to say what they wanted to do. What can you do? I also had conversations about the consequences of, "okay go with what they want to do." And we know that's idiocy, but it's not like running across a busy street. You don't do that, but most things aren't that serious

Fatima: It isn't. I feel like a lot of times we get into our feelings as parents. "I'm the parent." Well, you're not God. You're just a parent. They happen to pass through you. I don't know why moms especially we're just so wound up. Especially the stay-at-home moms. It's stereotypical. I don't even want to hang out with you. Your poor kids. I know my friends don't always like me and they always won't always like me. My mom always said, "it's okay. I don't need you to be my friend. I already have friends. If you want to be angry, that's your problem. I don't even care."

I'm not drug-seeking, I'm in pain 20:32

Health Hats: Okay, let me I want to ask you one more thing. Excuse my language but being involved with the medical system so much is like really a shitshow. That's just the way it is. It's just absurd. And I know that for myself that when I can find the humor in it and have a good laugh at how ridiculous things are. Not in the moment obviously, but sometimes afterward what have you guys had a good laugh over, that when it happened, it was outrageous?

Fatima: The other thing, too that blows my mind. It just makes me delirious – angry -especially when I'm dealing with doctors who are not used to Sickle Cell patients. I come to the ER, and I'm in excruciating pain. Granted, I still have to put on my eyebrows and look decent and change out of my pajamas and being in slightly uncomfortable clothing and wear a bra. One day I forgot. I always have to wear my wedding ring, preferably with my engagement ring on top, so they can see I'm married, and I have to speak properly. I have to do all these things to show them that I'm not drug-seeking. And preferably if my husband can come with the kids. That's always better. But being here with kids - staying, so that's not always ideal. Or at least my husband has a video chat. So, they know I do have a husband. All these little things that make them feel like you're not drug-seeking. And then one time I did get a doctor who was like, "well, you don't seem like you're in pain, you're calm." I said, "you know why I'm calm because if I talk to you like 'Shaquana,' then you're going to say that Oh, I'm the angry black lady and I'm drug-seeking." Really, I'm drug seeking, and it's life with the drug opiate crisis? You think I can't just walk down the street and get some powerful fentanyl. Why the hell would I come here for a little pinch of morphine? I leave my two children who are under the age of two with my husband, my comfortable house to come and beg you for a little dose of morphine. Yes, because I'm drug-seeking. This is the best place I want to be on a Friday night. The only thing I have to do is come to the emergency room and talk to you and hear that kind of sarcasm." He was shocked, "oh, you're really speaking to me this way?" He was just flabbergasted. He had no response, nothing to say. I thought this all in the calmest voice possible. And then he left the room. I didn't even see him for the rest of the night. But I immediately got all the medication I needed, and they brought me straight up to the room. That was the end of that. I was like, "thank you, sir. Yes, Friday night. I wanted to come and talk to you to for beg you for little doses of morphine that is not even hitting the pain. Do you even know how miserable I am right now and you're telling me because I'm calm and collected, but I'm not in pain? I wish you knew. I wouldn't wish it on my worst enemy. Talking about it sarcastically, it's all funny now, but at the moment it's infuriating. I have to breathe through putting on these most uncomfortable pants so that I don't walk in with pajama pants and just so you don't categorize me. It just makes me so sad because what if I was a single mom? What if I was 5-10 years younger? What if I did have two kids, but I was on welfare? Does that make me less of a human being? It just breaks my heart, and it might sound horrible that I'm leveraging certain social-economic privileges, but at that moment, that's all I have. My skin is brown and at the end of the day, I'm black. It doesn't matter that my parents are immigrants from Nigeria. It doesn't matter that I have doctors and nurses and lawyers in my family. Nobody cares. At that moment

all they see - because they're trying to take a quick assessment. They don't want to get in trouble for giving someone drugs. I try to see it from their perspective, too. They're just trying to make the quickest, fastest assessment without knowing you who are in pain. What do you need? It just stinks. The whole system really sucks. And I feel like it makes really good doctors and good PAs become horrible, mean, narcissistic, racist. Because no doctor, no nurses are actually racist. But there's so much racism in the system. Magically none of them are actually racist. It's heartbreaking. When I talk to my friends who are medical professionals, it breaks my heart because it's not easy for them either. There are people who abuse the system. I don't know how we can fix it.

Health Hats: Well, what do you say there Esosa?

Esosa: It's a Catch-22.

Fatima: Catch-22. It really is.

[It takes a toll on the whole family 25:15](#)

Health Hats: What should I be asking you that I'm not. About this journey, you've been on together.

Esosa: Yeah, I think I don't know if I talk to you about it before. I just all I know is that it takes a toll on the family. Everyone in the family suffers with the patient. I don't think people get it. Sometimes when I'm getting so tired. Oh my God, can you give us something before we die? Before the people caring for you. I will say things like that. But thank God I'm alive to see my grandchildren. But it takes a toll on the whole family, the siblings, the parents, the extended family - those who are willing to participate in all of this. It does take a toll. I wish when doctors are treating patients, they think of their families and not just concentrate on the patient and the patient alone.

Health Hats: Yeah, that's interesting. I was thinking as I was thinking about this call. This series that I've been doing. You're the third pair, young adult and parent, that I've spoken to and the people that I haven't spoken to are the non-main caregiver so like your dad or your husband, like Aziz or your dad, Fatima or what you're saying Esosa is so important that it's a family business. Anybody is suffering.

Fatima: Her perspective has made me think about - has helped my relationship with my husband too. Because now he's the main caregiver. But I just wanted to say one thing. I see what toll it took on my mom as a caregiver. It's changed my perspective - it isn't all about me, now that my husband is in that kind of caregiver role. Again, it's difficult because I never had to have these deep conversations with my mom because we just grew into it. We grew into sharing everything about my care. Having to sit down explain stuff to my husband and educate him. It's frustrating because when you're in pain, "can't you just know it?" But how could he know? It's not his experience. She checks in with Aziz all the time. How are you? Asks him questions. He always is moved by it. I feel she wouldn't know how to respond to him

as nicely and gently as she does. If she didn't have that experience herself. It's kind of like transferring of caregiving roles. Yeah. It's a whole other topic.

Health Hats: So interesting, you know, I interviewed a young lady who's in college now. She's had a chronic illness since she was 12, and so she's in college in Alabama and her mother lives in DC. She has a boyfriend, and her boyfriend has only ever gone to the doctor to have a physical for sports. It sounds like they've been together a couple of years and it sounds like he's a great guy who has learned the role and accepted it.

[Working with a chronic illness 28:55](#)

That's something you and I used to talk about. Who's the team? The team is always, obviously, the medical people, but it's also the lay people, your family, your co-workers, your whatever. You know, I think like you and I the reason Fatima you and I worked well together is that although you had to educate me about Sickle Cell because I was completely ignorant. But I understood having a chronic illness. Yeah, and so then it was easier to figure out well how we were going to do the work because we could appreciate that.

Fatima: Working with you changed so much because it made me realize that I can do things. I can do it as long as I have adjustments. And what adjustments do I need to make for myself and what adjustments do I have to ask for? Because you had a chronic illness. So I think that was a blessing in disguise that you were my first like real employer out of college. I didn't have to ask for certain things. You just understood and knew. But now it taught me that okay if I'm going to a new environment, how do I bring up these conversations? How do I have them? What do I need to ask? I feel like it really was a life lesson for myself and opened up my mind to the possibilities of what I could do and what I could be with the right adjustments. If that makes sense?

Health Hats: Yes, that makes total sense.

Fatima: I'm thankful for that. Yeah, we learned a lot. It was an education.

[Turnaround: You taught me to accept myself 30:23](#)

Health Hats: You should listen to my podcast of the interview with you. The way I introduced you is to tell what you taught me.

Fatima: I can't wait to hear it. Now I'm going to hear it. I'm going to be okay.

Health Hats: Also, Esosa, I learned a lot from your daughter.

Esosa: Thank you so much, Danny. That's just so nice. Yeah, thank you.

Fatima: She knows how much I adore you. Oh, Danny said this.

Health Hats: It was mutual. I was telling somebody that the way I've been introducing myself these days is that I'm a two-legged, cisgender old white man of privilege.

Fatima: The room probably goes silent when you say that. Because they're not many people who understand that. Black people probably come up and hug you. Do they do that?

Health Hats: Not really. But I would say that working with you and getting to know you I learned to accept this is who I am. I don't need to be ashamed of it because sometimes I would be ashamed of it.

Fatima: What's a blessing because you helped bring other people... We can't make changes by ourselves. So, when we have people who have power and privilege. it helps the cause of equality. Remember, Catherine and I and Mary were flabbergasted talking about how you chose to hire us. You were like, "what's the big deal? You were the best." No, it is a big deal because we know we were the best but still not chosen, because of technical whatever and we all knew what it was. I think the fact that you were so shocked about that was so endearing. We're like, "wait. You didn't know that?"

Health Hats: They sat me down and had a conversation. "You have no idea." Yeah, it changed my life, that conversation.

Esosa: Thank you. Thank you for having that. I'm grateful that your mind is so open that you are willing to make changes on everyone's behalf. I'm so grateful that Fatima met you. Hmm, your beautiful wife is such a beautiful human being. I've been so blessed.

Fatima: Just like I was like, I wish I had that calmness. Maybe the hard knocks of life make you calm like that.

Health Hats: don't know. We don't have those calm genes. Alright, thank you so much for your patience and time and Fatima we will talk soon.

Esosa: Okay, okay, so much.

Health Hats: Thank you Esosa,

Esosa: No problem. Thank you. Have a good night. Everyone blessing. Okay. Bye.

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[Being a boss of a person 33:47](#)

First, I was Fatima's boss. I worked at Advocates, Inc. Advocates supports about 23,000 people with disabilities. I was VP of QM looking for an executive assistant. When I interviewed Fatima, I found her bright, energized, and a bit irreverent. She had a bachelor's degree. She was so far ahead of any other candidate. The pay I had to offer was underwhelming. And I needed to know was that she would enthusiastically support the mission of the organization. She told me that her parents had worked for

Advocates. I offered her the job. She accepted. I soon learned two things about Fatima. Day one, she's sitting in her cube looking forlorn. What's the matter? I don't know where to pray. (I had the only office.) Use my office. I can sit at your desk. How long do you pray for? 5 min. I thought it would be 30 minutes. I was so ignorant. A few weeks later Fatima calls from the hospital. I'm in the hospital I can't come in. I'm so sorry. No worries take care of yourself. Let me know what I can do. In the morning I found some work from her in my inbox. She had her laptop with her and worked from her hospital bed. Let's talk about being the boss of a person with disabilities. No, let's talk about being the boss of a person. People have families and abilities that vary with time. Working with kind, skilled, compassionate people is a blessing. We can figure it out together. Someone else needs to know everybody's work. While balancing efficiency, productivity, meeting schedules can be challenging with caregiving of children, parents, and self. It's possible. Life happens. Tragedy happens. You need to be up front about it and plan mindfully, together -the whole team. It's so worth it. It's a joy to lead a dynamite team. Fatima and I started as boss/employee, became colleagues, and grew to be close friends.