Living a Happy, Full Life
Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medicine

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Content

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I just want to create awareness about what sickle cell disease is. That people that it's human beings who have it. People who have regular lives and struggles and hopes and dreams also have sickle cell disease and are just trying to live a happy life, a happy full life. That's all.

Introduction 01:09

Health Hats: Fatima and I first met as colleagues on the same team working for Advocates, Inc., in Framingham, MA. We worked together in Quality Management for this organization that supports 23,000 people with disabilities. Quickly I learned that Fatima had Sickle Cell. We bonded over working with chronic illness and clothing. Fatima wore gorgeous colorful hajibs and I wore colorful bowties. People would ask us if we texted before work to color coordinate. I've learned so much from Fatima. She was curious, questioning, and driven. I actually became more comfortable owning that I was an old white man of privilege working with Fatima. It is part of who I am. It's OK. It depends on what I do with it. She opened up new vistas of appreciation of health equity challenges. We've stayed friends and coached each other through our various chronic illness and life challenges. I'm so delighted to have the opportunity to chat with Fatima now. I spoke with Fatima's mother, Esosa, previously. I will edit and post that interview next week. OK. Here's the interview. You'll appreciate Fatima's poise, eloquence, and humor as I do.

Good morning. I'm sitting here with Fatima Mohammed Ighile. Thanks for joining me. Fatima and I have known each other seven or eight years or more. We worked together for like three or four years?

Fatima: At Advocates

Health Hats: Oh, yes at Advocate, Inc. And we've stayed friends since.

Fatima: Yes.

My body's not working: Sickle Cell 03:02

Health Hats: I wanted to talk to you some about your experience as you transition from pediatric to adult care in managing your Sickle Cell Disease. I think though I first want to ask you, can you remember where you were the first time you realized that health was fragile?

Fatima: Where I was? Yes, I think I was 7 years old. It was winter and it was my first memorable pain crisis that I had to go to the hospital for. And it was winter in Framingham, Massachusetts. So that's just that's really cold winters, and I was just in excruciating pain on the couch with the heating pad. I miss school that day, and I just did not understand why my body was not working. I wanted to go to school. I love school. I wanted to go play outside in the snow. My body was not working, and I did not understand or yeah how to fix it. So that was the first time I realized that health is fragile.

Health Hats: So, that was your first experience with sickle cell like knowing that well, maybe you didn't know at that time that it had a name?

Fatima: Well, thankfully the year I was born was the year they started Sickle Cell screening of all children in Massachusetts, which is actually from what I know is very groundbreaking because a lot of states did not have it at that time Sickle Cell screening as like a mandatory screening for newborns. My sister was born the year before in 1989 and after six months she was a colicky fussy baby. Nobody understood why she was fussy. This kid will not sleep through the night sometimes. She's just cranky sometimes. And so, it was after I was born a year later after they done the screening and found I had sickle cell they then decided to screen her for sickle cell and found out that she also had to go. Yeah, so she owes me a lot because I helped.

Is it that kind of pain? 05:32

Health Hats: In your early years of managing this what was your relationship with the medical system doctors, you know, hospitals, staff.

Fatima: It was really magical. I was always in pediatric units and with nurses. I found that in Pediatrics, I don't know what kind of screening they do, but I've always had amazing nurses. I can still remember some of their names to this day. And now looking back on it as an adult, they've gone above and beyond their jobs. My parents have five kids, so when I would be in the hospital, they couldn't always be there every single night, overnight. They worked and had other children. I just remember having amazing relationship with the staff, with doctors, nurses, all medical care givers. And my mom and dad were the buffers between me and the medical group. But one thing I do appreciate is that my mom always tried to explain everything to us. What was going on. And even though she definitely took the lead in our, in our care she would discuss things with us openly and sometimes to the point where I thought why their moms are mean when other kids are sick. Their mom weights on them hand and foot and so lovey-dovey but my mom and I was in pain she would if I came to in the morning said I'm having pain she would give me my medication and ask is it pain that you're going to have a rough day at the school? Is it that kind of pain that you could still go to school but have a rough day? Or is it bad that like you cannot go to school, you need to take a day off? Or is it bad that you need to go to the hospital? So. At age seven, eight, nine, we had to answer those questions and she would make us open up our own pill bottle and even though my arm was in pain and make a sandwich and get a cup of water and she really did not baby us. And but my dad he just could not handle when we were in pain and he really babied us a lot. But now that I'm older I'm so thankful to my mom for that because it made me, she wanted to make us independent. Now I know she used to go to the other room and cry, so distraught. But she wanted us to have a life outside of sickle cell. So, I'm very, very thankful for that Independence that she gave us and didn't allow us to feel sorry for ourselves. So, I'm so, so thankful for them.

Advocating for myself 08:03

Health Hats: So, do you think your mom asking you to describe it and calibrate how serious it was that was sort of the beginning of your being able to speak up for yourself and have words to describe. It seems like part of speaking up for yourself is communicating your experience.

Fatima: Exactly. My mom, she at that time in Framingham, Massachusetts was a very white town. It was just the beginning of the Immigrant wave-like and there weren't many black people in particular. It was just like a quiet suburb outside of Boston and because of the demographics there were not many even physicians who were familiar with sickle cell disease. So, my sister and I were the first patients for our pediatrician to have sickle cell. So, my mom would carry around these binders and information. Her number one thing for us that she found that she really wants for us with this illness is advocacy because she had to advocate for us so much. She really wanted us to learn how to advocate for ourselves. So, I think that was like that was a huge, huge concern and that was all part of, you know, the greater plan that I've come to realize.

It's more than pain 09:35

Health Hats: It seems like that with the stuff we've communicated about related to managing sickle-cell whether what was pediatric, or adult has a lot to do with pain management. Before we talk about that, what are some of the other things you had to deal with in the transition from pediatric to adult services besides pain?

Fatima: One was hydration. Because as a kid, my mom would get us these interesting cool-looking water bottles, and I knew I had to drink water but then I wouldn't always do it. I was very active very much a tomboy and I love to run around. I knew I could do that, but I couldn't overdo it. But these are all lessons throughout growing up. I had to learn the hard way in a lot of cases. Maybe it's not the smartest thing to go outside in the snow without a jacket and participate in that snowball fight that's so fun. So, it's during these experiences and my mom would just be honest. Like okay if you choose to do that you choose to be sick what's going to happen. Like everything your parents say it's like they don't know anything because you know everything because you're 10. So wise about the world. It works but after learning the hard way a couple times that was like a huge self-care. That's what it was like. Things that people don't usually learn until their twenties, I had to really consider at pre-teenage. Okay. I know my period is coming. I should probably stay extra hydrated because having a menstrual cycle could trigger even worse Sickle Cell crisis if I was dehydrated, if I wasn't dressed warm or those kinds of things. Thankfully the doctors would also explain this to me during doctor's appointments. Okay. What are you doing to take care of your care? And what are you doing to take care of your sickle cell? That was a huge part of the doctor's appointments. I found out later that my mom and the doctors would plan these prep talks. Wearing a jacket, staying hydrated, not overexerting yourself and. That was a huge component and that I'm very thankful for the doctors besides just giving pain medication. It was an education how to educate you about your own data. Educate me about my own disease in a way that my child brain could understand. So that is very they would draw if it took drawing out the pictures of the sickle cells and explaining the vessels. That was a huge, huge component of my pediatric care that I'm so thankful for and I really feel is lacking in adult care.

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Going away to college. Oh my! 12:25

Health Hats: So okay, good lead to adulthood. When did this transition to adult care happen? It wasn't like bang all of a sudden there's adult care, but how did that progression occur?

Fatima: I guess they started prepping if I think back. When I was 18 I went to college I went to University of Pittsburgh. In Pennsylvania.

Health Hats: Your mother told me that she fought you tooth and nail.

Fatima: Yes. She did. Then on top of it, after she finally realized she was losing that fight, everybody blamed her. You let your daughter go. People assume that other people have control over their kids when they know they don't have control over their kids. Like you're gonna allow her to go to school in Pennsylvania?! It's a craziest thing. And I'm thankful that she didn't force me to stay.

Health Hats: Yeah, so then you had to do it. That was dramatic.

Fatima: It was really dramatic. I had to transition them from youth care to another care and actually a huge part of my orientation was visiting my new doctor. I remember his name is Dr. Krishnamurti at the Children's Hospital in Pittsburgh. And so, at that time I was 18. I was still under Pediatrics in some places. They let Sickle Cell patients stay in Pediatrics up until the age of 19. Others is 21. And I was just 25. So, I guess different programs have different age time. When I went to Children's Hospital and met with Dr. Krishnamurti and his team and his staff and it was really amazing the care, the education, the support is all there under Pediatrics. But then when I had to transition to the adult care in Pittsburgh, and I had to really do that by myself. That was like 20, 21 with some consultation from my mom over the phone, but at that point I'd been living away from home for a few years and actually had the confidence to do it and there they did an amazing thing. They would go with you to see the new doctor. I think a nurse or someone from the team with they were going groups you go to the adult patient care as you see the inpatient Hospital. You'll see the hospital where you would stay if you had a crisis. The Outpatient Treatment Center, you'd meet the staff like that with that supports. It wasn't just like oh, there you go. It was a few months of transition.

Health Hats: Wow, so they really guided. Like it was a warm handoff as we used to talk about.

Doors open 15:37

Fatima: Oh, yeah, it was but it was so traumatic. I did not want to go. Did not want to go at all. But then transition to adult care in Pittsburgh with the University of Pittsburgh Hospital was one of the most amazing things the doctor there at that time. There was Dr. Novelli, Enrico Novelli. I became a patient with the adult care there. I was also pre-med at the time looking into going to medical school. Possibly work in healthcare field in some capacity. So, then I was also able to do research in his wet lab and do research, clinical research. I became kind of like a student of his. I'd work at the wet lab a couple days a week and then I'd also work in his Sickle Cell program. Shadow him as he went to visit other Sickle Cell patients. They didn't know I had sickle cell. Yeah, and I did a collaborative project with him when I did research in Nigeria at the sickle cell center in Lagos Nigeria. It was just really amazing. it opened up doors I didn't even know were there. So that was one of the most amazing transitions of my life.

Coming out with Sickle Cell. Building community 16:58

Health Hats: One of the things you're not saying that I just want to check out with you, is that being a teenager, even when you're an outgoing person can be sometimes very lonely. And then on top of it, having sickle cell can also be lonely making. Was that an issue? And if it was how did you find people, community?

Fatima: So, my sister has Sickle Cell. She's a year older than me and we were just built in best friend slash frenemies, depending on the day. Yes, depending on who stole whose clothes that day. It was already a built-in support system and then on top of that I had a cousin who had sickle cell disease and he was a year and a half older than me. We're only in eighth grade. So, I never really thought I was without Community because I really had a good time with my family. Okay? I remember, I never told people I had Sickle Cell. I was very private that time. I thought it was being private, but I realized I was just being protective. I didn't want people to think I was weak. Like I mentioned I was athletic, and I was a tomboy played basketball from my high school. And I just did not want to be seen as weak. I was a neurotic straight-A student. The type of person I would never want to hang out with now. I'm just very like oh my God, I got an 89 not a 90. In high school I just kind of put my head down, didn't really tell people unless I had to and that was usually, I told my teachers if I miss school. But actually, that attitude really hurt me my first year of college at University. Because I didn't want to tell anybody anything. It's my life. I don't want to be weak. So, I it was my first semester. I really struggled. I really suffered because I when I went through Sickle Cell crisis, like I said, I didn't go and tell my professors right away. So, I have a major paper due now. I'm saying I don't feel good. So that was really difficult to navigate. So, after that all blew up in my face and then friends also like okay, I can't why I haven't seen you for 3 days? Where have you been? Oh, I haven't been feeling. Well. Okay. Hope you get over your cold and then it happened again and then again and then it would just sound suspicious. I had to really learn. I had to get over myself. I'm just really had to communicate to my roommate who I lived with in the dorm, that okay I have sickle cell. I get pain crises and you know, and I it was very, very difficult for me to do. It sounds so simple, but because I was private. It was difficult for me to do and to open up that way. But I had to do that in order to build a community, a home, away from home because I didn't have my friends. Like who was going to bring me my homework at the hospital if they didn't know why? Once I did that, I saw the benefits of it that I would be able to get notes and get help. I didn't have to do it all by myself. So, actually if you talk about loneliness, I didn't really feel that in my early teenage years. It was more my University years because I really went into myself. I didn't have family around. I didn't have that social, the support network I had normally. My sister was at University in Boston living her life. And but she was still close enough to home where she needs to come home for a few days she could do that, or my parents could visit her at the hospital if she did end up in the hospital. Whereas, I was in the hospital by myself. No one visited me because I didn't tell anybody, and it was very lonely you can say. But after I slowly started to open up to friends, I was able to build a community around me and people were surprisingly, they received it well. They were kind. They were ready to help and that shocked me but also helped me realize that it's not… You can you can build a support. It's not just family that's there for you other people can be there for you, too. Realization.

Trying to live a happy, full life 21:12

Health Hats: So, one more question and then I know you have to go. So last time you and I spoke you were talking about wanting to do some advocacy work. So, it seems like we've only just talked about a sliver of the experience you've had over the years. Tell me a little bit about what you're thinking about in terms of doing advocacy work.

Fatima: When I think about advocacy with sickle cell or chronic pain, chronic illness in general. I see that there is a demographic that's not represented much. It's the young, particularly black immigrant experience. It's the mom experience. It's the experience of somebody who's ambitious and wants a lot in life. I want to create content that I wish I had. Like, okay, you're in pain, you're in a new city. How to convince this doctor in this ER that you're not drug seeking. I wish I had that kind of tips like dress properly, how to speak. Yes, you need to drop your credentials because people say they're not racist. But yet the data shows this implicit bias really affects your treatment and I've seen a difference in how people treat me when they think I'm a black single mom on welfare versus when they find out I'm college-educated, my husband is a professional, I'm a stay-at-home mom. It's disgusting but in a time when I really needed relief and support and just to get healthy and when I was actually a few times really afraid that I might die this is what needed to happen. And so, I found tips certain things like make your husband go with you to your pregnancy appointments. Because it makes a difference when doctors see you're supported versus when they think you're not supported. When they see my husband visiting the hospital. When they see my Mom calling and asking questions. Or my friend who is a medical doctor, really involved in my care. It changes the way they treat you because they know they cannot get away with BS and it’s really sad. It's really unfortunate, but I really just want to be a resource for people. That I wish I had what to do when you're going to University. Great. How to write to your professors and tell them you have Sickle Cell. Visit the disability office. Get that official letter so that if you are in the hospital during finals week, it doesn't affect your whole GPA. How to cope with sickness when you have toddlers. Activities you can do that or not so burdensome on you physically. So, it's from the patient's point of view. I want to help people who are patients, who are Sickle Cell patients, how to navigate the Healthcare System. Just little tips and tricks. Of course. I don't know everything. I'm also learning myself. And also, how to manage with life you want to live. I want more than just to survive and get over my pain. I want to thrive. I want to have a good life. I want to have experiences and live and then also I want to humanize Sickle Cell patients to nurses, to doctors who see us as a monolith. Who I've heard them accuse me of drug seeking when they thought I was not listening. The way they speak to us and I want, and I think half the problem is that we as Sickle Cell patients don't put ourselves out there. We don't tell our story. A lot of people especially white people, Americans are very open with disease and they talk very openly about it. And I feel as a result the society knows about cancer. They know about the different fibromyalgia and all these other sicknesses and it humanizes it.

People have more compassion for those diseases and understand it. So, if you don't tell our story somebody else is going to control our narrative. That's what I don't want which is what's happening right now. So that's all I want. I just want to create awareness about what sickle cell disease is. That people that it's human beings who have it. People who have regular lives and struggles and hopes and dreams also have sickle cell disease and are just trying to live a happy life, a happy full life. That's all. And if a few weeks of dollars goes toward sickle cell that makes me even happier.

Health Hats: Fatima, lovely to talk to you as always and thank you. I did talk with your mother and we discussed maybe when she gets back from her travels, maybe we could have a call with the three of us. And sort of look at how you viewed some key points along the road.

Fatima: It would be good to know what she says. Yeah, not something we talk about.

Health Hats: She was interested.

Fatima: Thank you so much Danny honestly any kind of opportunity I get to talk about Sickle Cell. I think you just for highlighting it the disease and letting people know it does exist and I'm very, very thankful for you for that. And please let me know any other opportunities you have where I can moan and groan about it. Please let me know about the think well.

Health Hats: You're actually not that much of a moaner and groaner. Okay. All right, hi to Aziz.

Fatima: Thank you. My best to Ann. Okay, bye-bye.

Front row seat 27:00

I learned something new about Fatima. I learned that she was pre-med in college and shadowed her physician and worked in a lab. I already knew that she has a wicked sense of humor and pulls every lesson she can out of her experiences. I just love and admire her energy. I'm delighted I have a front row seat in her in her ongoing journey.