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#### Proem



Figure 1: Ann and Danny at Fatima and Azeez' wedding

I'm delighted to reconnect virtually with my dear friend, Fatima. We last recorded several conversations, two with her mother, Esosa, in 2019 as part of the series on people with complex conditions transitioning from pediatric to adult medical care. The titles included Living a Happy Full Life, Good Listeners, Good Conclusions, and I'm Not Drug-Seeking. I'm in Pain. Becoming friends with Fatima has been one of the delights of my last decade. I especially value sharing our diverse experiences, finding many common cords (chords), leading to ongoing separate growth and development. From Fatima, I've dared to proudly introduce myself as a 2-legged cisgender old white man of privilege.

### Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

#### Four more years, a mother

When we had the conversations in 2019, you were a mom, but it wasn't about you being a mom. Now, you've been a mom for four more years, dealing with sickle cell and being part of the family unit. Your mom said it's not just the person with the diagnosis; the whole family must manage. What are your thoughts about that now? You and your kids are getting older. Your son's graduating from preschool. I can't believe it. Anyway, what are your thoughts about that?

Fatima Muhammed-Ighile: She states that sickle cell is a family issue. These last few years, I've understood that more profoundly. My kids are now five and six. They ask questions, and there are times when they can now comprehend how my restrictions, based on when I feel sickle cell pain, affect their lives. So that's required me to have discussions with them that, at times, I wish I could have delayed.

**Health Hats:** If I remember correctly, your daughter probably has the most challenging questions.

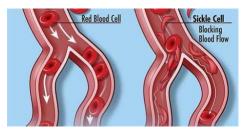


Figure 2: Image from https://www.kold.com/2021/01/28/federalcommittee-recommends-more-research-carepatients-with-sickle-cell/

### You mean I won't get sickle cell?

**Fatima Muhammed-Ighile:** It was a lazy Sunday afternoon, and she talked about when she gets older and has sickle cell. This is what she will do. I'm like, that's not how that works. What do you mean when you get older? I have sickle cell. She said, you're an adult, and you have sickle cell. So, when I'm an adult with sickle cell, I told her that you won't have sickle cell when you grow up. She was so shocked by that.



We looked at each other as if we had two heads, and she ran to the room and told her younger brother, guess what? We're not going to have sickle cell when we're older. Did you know that? I thought I was doing an excellent job explaining things to them.

I didn't know they had internalized the fact. They thought they'd also have pain, sickness, and hospitalizations when they got older. They were excited about that, which made me sad. But then, after the sadness, mom guilt, and all the unhelpful feelings, I had to think back: okay, we need more conversations. Things are not landing as they should. And that was a moment for me to realize that we need to talk about this in doses. That was an eye-opener. That happened about 18 months ago.

#### No lying in motherhood

**Fatima Muhammed-Ighile:** Right now, if I'm having pain and I said we're going to do something, I have pain that day. I have to say no. That is hard for me because you and I discussed treating children not as objects but as actual human beings.

They are people. So, I'm not going to lie to my kid. However, I would be uncomfortable if she asked why that man wore high heels and lipstick. I'm not. I will not lie to you. That's just mine and my husband's ground rule. However uncomfortable we may feel, it's their right. They have a right to be told the truth, the best we understand. They are little truth-tellers and force the truth out of you. I have to deal with those feelings of discomfort on my terms. So, with counseling and therapist journaling, it's not their fault if I feel sad that they think it's unfair that they can't do something because I don't feel good. That's completely justifiable for their kids. It's okay for them to be disappointed.

#### Harder on myself

Health Hats: Are you harder on yourself than they are on you?

**Fatima Muhammed-Ighile:** They know I don't lie to them, and I keep my word. They are very forgiving. It wouldn't even cross their mind that I genuinely didn't. They forget about it after the next act. But I still hold onto that feeling as a mom because this means so much to me. Like I know most parents, it's their job, but we purposely set up our lives so that their needs can be taken care of at a moment's notice, emotional and otherwise, so it's very intentional. So, when I feel like I'm failing that, that hurts.

### Treat us differently



Figure 3:Image by Guillaume de Germain on UnSplash

Health Hats: I remember back, and you can correct me if I remember this wrong, but I think back to when you and I worked together, and my grandkids were little. I remember conversing with you when I noticed that the grandkids treated me differently than Ann because they would just run along with her. She would have to be careful that they didn't cross the street without looking, but with me, they would just stick and make sure that I didn't cross the street without looking. I think that they got a sense of it was different. It wasn't like it was any big deal. It's just that Opa can't chase them. It was an eye-opener to me that they would think about me so differently, And at first, I think I felt weird about it. Do they feel less free

with me? And then I thought, no, maybe they're three, but they got that something else is happening here, and they got to take care of Opa. And that was a good thing. So, you're talking about them feeling



disappointed, you feel like crap and so they can't do, you guys can't do what you might have had planned. Do you think their disappointment is okay? I'm disappointed. Okay, let's move on. As opposed to, mom, you suck. I'm disappointed. It's all your fault, Mom.

**Fatima Muhammed-Ighile:** I have noticed that they feel the need to go out of their way to help mommy out on the days they can see that I'm not doing well. Oh, Mommy, I'll fill up your water. You need water. Remember what the doctor said? You need a lot of water. You have to stay hydrated. I had to tell my daughter once because if I do this for you and let you nap, will that mean you won't ever have to go to the hospital again? I had to tell her I would still go to the hospital. There's nothing that you can do or I can do. We can just try our best. But it's a fact of life. It's not that you didn't let mommy take a nap. Now it's never your fault that I go to hospital. That's not how this is. I see she takes on much of that responsibility and burden. Although I appreciate that she's compassionate and loving and wants to help, I don't want her to put things on her shoulders that don't belong in her tiny little shoulders,

Health Hats: It seems you don't have that much control over that.

Fatima Muhammed-Ighile: Lie to me, Danny.

#### Where do they fit in the world?

Fatima Muhammed-Ighile: I think you're right. I'm making it bigger in my mind because they're now at an age where they compare. I even heard them talking about who in their classes is rich and poor. Azeez and I just sat in silence in the living room. They didn't know we were listening. What a fascinating conversation! How do you even know? It was very interesting. They're starting to compare and contrast and trying to find where they fit in the world. In that sense, we always talk about how not everybody is the same and what God gives one person and doesn't give the other. It has no bearing on your goodness or if you're deserving. That's not how that works. So, we talk about resources and money and who has or doesn't have. If a child doesn't have food or the best home, it doesn't mean they're not a good person. They're not being punished for that. It's just that our lives are different.



Figure 4: Image created in DALL.E

It hurts me to know that I might not do what they think other moms can or should do. But I don't even think it's gotten to that point yet. I don't think they think some moms do this or some do that. I can show up to some school events, but some parents will never attend any school events because they're working. And that's okay, working. I don't work. But that's not everybody's life, so I know I catastrophize their disappointment because of the pressures I put on myself. It still doesn't necessarily lessen the guilt per se. But I have to move. I don't want to drag myself or them down with guilt. It's very unhelpful. It's useful for collecting data, but how is that useful or helpful for anybody?

### Call to action

I need help to keep creating without impacting our retirement funds. I've expanded my Podcast this year to include video, and the costs and time needed have surged. Although my queue of episodes ready to produce grows, I can only manage monthly episodes. I need to build my production team further. You can help.



Visit <u>health-hats.com/support</u> for ways to contribute. Choose monthly subscription with bonus content, Zoom meetings with me and others, personal Bari Sax MP3s, coaching sessions, and more.

Occasional donations are also welcome, and you can still subscribe for free to enjoy bonus episodes. You can also recommend us through email, social media, or postcard - postage on us! Visit <u>health-hats.com/support</u>. Your support is deeply appreciated. Thank you.

### Moving on and building community

**Health Hats:** So, let's change the subject. Back when we talked recorded before, one of the things that we talked about was building community. Since then, you've moved several times, and sometimes we talk because you're suddenly in a different community. You have an experience in those communities where you must rebuild everything. Tell us a little about when you move and rebuild a community of support, whether it's professional, personal, or child support. What have you learned from the difference? Because you've done it several times.

**Fatima Muhammed-Ighile:** Several times. And I am thankful for those times because sometimes you build a community with people, or maybe you do not. But then you get to move. I've learned from this scenario and can take that into my following scenario. One thing that has happened a lot this year is that I've shuffled many of my friends, and I feel like I've been shuffled out of some friend groups. I think that's the nature of being 33. People have families and careers and must be reprioritized, and values are a huge difference. One thing, after having my heart crushed a couple of times and breaking up with a few friends over core values things, not like anyone did anything horrible, I'm starting to be able to sift through that a lot faster and more keenly.

One thing someone advised me because I'm a very kindhearted person. If I feel loyal to you, I am forever loyal to you, like you have to do something horrible for me to discard or leave you. Or if you've been good to me. That's how I am generally speaking. My door's open. You're welcome to my home. That's how I am, for better or worse. I've been learning that those who you go into community, it's not everybody you go into community with that has to become your best friend or even a friend per se. It might be a quid pro quo: okay, I'm taking your kids, and they go to the same daycare.

We live around the area, pick them up, and drop them off. It doesn't mean we have to braid each other's hair and be best friends like they will be people for a reason, and then very few people for life. That's a gift. I was setting that as the expectation and getting sad about it. Despondent. It's unfair to ask anybody to put such a lifelong friendship sisterhood on people's shoulders. So, I'm thankful for the moves and having to do it multiple times. Hopefully, we'll be moving again at the end of the summer. Not far, but a new community. And we're moving for the community because it's closer to the hospitals.





Figure 5: Image by Hasan Almasi on UnSplash

### Muslim community

**Fatima Muhammed-Ighile:** Closer, it has a larger Muslim population. There are Muslim schools there. And as our kids get older, that's very important to us. I've learned so much and am so thankful for the people along the way. It's also taught me how to be a better friend and a community member without being controlling. You can be there for people, support people, and when they do dumb things, you just have to look at them, do the dumb thing they do, and be like, okay, cool. And just accept that. And I feel like not being friends with people makes it easier for me to

have those boundaries.

But the community I built has been invaluable. There is no way I could have done it without the people who've helped me, or it wouldn't have been as fun. It wouldn't have been. As they've taught, the women have taught me so much, and I'm so thankful for them, even for basic homemaking skills that we no longer know. As a second daughter in a Nigerian household, I used to skirt those responsibilities. Oh, she can do it. My sister can do it. I don't have to do it. And to my detriment in some ways. So, I've learned how to meal prep, what to freeze, and how to have a quick meal in a freezer bag because I prepped days before that. I've learned so much, and for those things, I'm thankful, and I feel I have to pay it back and be generous. I never thought my generosity had strings before, but it did.

It came with the expectation that now you have to take my advice or do this. Because I know best, I know so much in life. I've been here for three decades, so it's obvious. I know so much. But I just understand that everyone's life is different. No one owes me anything but the people who are there. Be thankful for it, appreciate it, and see how you can be there for others.

It's so unique, too, like people who you would least expect it have stepped up to a plate where I'm like, wow, you're going to babysit my child for a week. Because I'm in the hospital, who does that? So, some people have surprised me in amazing ways. So, I try to think about those positives within the negatives.

# Healthcare Community

Health Hats: Another part of that community, though, is the healthcare community. So, in your case, much of your healthcare community happens around pain management. And it seems like that's been like building that community has a silver lining, but what about that? You went from your Worcester community, where people knew you from a young age, and your mother helped build those relationships. Then you went to Florida, then to Texas, and there were if not mini disasters, they were significant disasters. How has that happened? So here you are, a woman of color, a Muslim, and somebody in severe pain. How's that been in terms of building that kind of community?



Figure 6: Image create on DALL.E

**Fatima Muhammed-Ighile:** It's been hell. I don't appreciate it. I would rather not, but I've found that people tend to fall in line once you have a doctor who believes in and supports you. That's what I've found. So I try to make sure one thing that has



helped me is making sure that all my doctors are under the same healthcare system. I didn't do that in Florida; I wasn't even aware of it. That would be helpful. That was a disaster. There were miscommunications and the ability of doctors to do somewhat unethical things, but nobody else looked at their notes so they could. They didn't care. I just became a number.

# Trust my team

**Fatima Muhammed-Ighile:** When I found a sickle cell team at the head of Dr. Nero. I've never actually met Dr. Nero. She's a black woman. She's a sickle cell specialist. But my hematologist is under her team. I can tell she has an impact because even in the ER if they know you are under her, they treat you differently. I don't know how often she talked to them, lectured them, and told them about their lives. And the other thing that's very helpful about Dallas is that the healthcare is super diverse. So, there are a lot of black doctors here, usually immigrants or Caribbean. There are a lot of Arab and Middle Eastern doctors, with white doctors in the minority. I don't know if I have a white doctor. I don't know. I don't think so.

Health Hats: Wow, that's different from Florida.

**Fatima Muhammed-Ighile:** Completely different from Orlando. Orlando was just like a walking, talking, hot mess disaster. They lived and breathed stereotypes. Not that Dallas is ideal, but it's completely a step up. What's more, they're tied to the University of Texas, so there's more prestige and more awareness of the latest research, and it seems like they're all in communication with each other, which is completely helpful. One thing I found is that I am now meeting with a new set of doctors for a different specialty, and my demeanor towards them is that I tend to be a warm person when I first meet people, but I was completely cold. Finally, at the second meeting, I told them I knew I was coming off as cold because I didn't trust them. Doctors, especially doctors in your field, and the lady asked, what can I do to earn your trust? You can tell me the truth when you don't know something. Tell me you don't know instead of telling me false information that I must find out later, it is false because that puts me on edge. Whenever you speak, I'm double-checking fact-checking as you speak. I'm writing things down. I don't want to do that back and forth. So, when you don't know, just tell me you don't know.

### Ego-centered, patient-centered



Figure 7: Image by Lia Bekyan on UnSplash

And she said thank you. I've also found that by sticking to the plan and by working the plan, you come up with the doctor, whether the pain plan or whatever, and going to appointments when I'm healthy. Doing the check-ins, doing all that, they're, the doctors are a lot more receptive because they feel like you know about your care, although some still feel like they know everything. One doctor was arguing with me, and I was telling him my hemoglobin level is usually at 11. He's the last few times. It looks like it's by at eight or nine. I'm like, but it's typically at 11. Then the next day, I told him, I was like, oh, why? It showed the last few months at eight and nine. I've been off Hydroxyurea, but if you look at when before I stopped Hydroxyurea, it's at a 10 or 11. The female resident smiled. She was happy that I

stood up to him. He was like the director of blah, blah, blah, who the hell knows. And then his face



turned red. But that was suspicious to me. Why is that? Why are you upset? You're more, you care more about being correct than about, let's get to the bottom of this. Small discrepancy. So is the ego, is your ego going to be at the forefront of my healthcare? I don't feel safe around that.

I just try to note the patient-centered doctors instead of ego-centered versus the ones that are not. It's the same with the nurses, and I'm more open to requests for a different nurse. If you are shady or not receptive, please, I'll have a different nurse.

And if you are upset that your director is wondering why you want to switch out? That's your issue. That's not my problem. I don't care about your feelings. I care more about my life. Outside of that, I try to be highly polite and extremely respectful to the point where the nurses on the floor always say everybody wants me as a patient when I'm inpatient. Because it's so easy and I do their job for them. All I do is call when they need medication, and that's it. It's very simple and straightforward. So, I just try to be as compliant and polite as possible. But I will not let you get away with crap. I'm going to let you know I'm watching you.

# Speaking truth to power

**Health Hats:** Okay, so this might not be appropriate, and if you don't want me to include this, let me know. But one of the things that I reflect on when I reflect on my relationship with you, starting when we worked together in a challenging setting and then as we became friends, is that we've taught each other a lot about speaking truth to power. I've learned from you, you've learned from me, and it seems like the most challenging time to do that is when you feel like crap, right? Maybe it started when we were on the same team, and I was your boss, and you could say something to me. Then, I dealt with what I was dealing with: my boss. And we, as a team, dealt with how we would handle this difficult situation. And then, with our healthcare, it seems like a lot of what you have to do is speak truth to power. Am I wrong?

Fatima Muhammed-Ighile: No, you're entirely correct. It's not actually when I'm in pain; it's easier to do, but it's harder to do it politely and diplomatically because what I say and how I want to say it is entirely different than the more productive way to be. So, I try to make sure that I am not having when I'm not in the middle of the pain crisis, and I am touching base with a provider via email, via request, a phone call, meeting telehealth, or personal. I have the energy, to sum up the diplomatic so they can remember those other times when I did not have the strength to be diplomatic. But there are some doctors where I found that



Figure 8: Image from YouTube video by Fatima https://youtu.be/2Ql2NgnZ\_Ok?si=ont\_MhFWN HFooUJQ

like the whole, oh hi, how are you? That's not going to help you. It might be better in my case. I found that sometimes it's better to be known as the angry black woman, but at least you know that she's watching what you do, noting, and asking questions than being liked per se. I honestly could care less whether I'm liked, but I have to remember that it is easier. It's better to catch with honey, blah, blah, blah. Better catch more beef, honey. But at the same time, I feel like I have to add a bit of that kick because I'm not playing, and that's part of why I'll have to ask my husband sometimes to take off work and come to this appointment with this particular provider. I've seen how I'm treated differently when



they know multiple people are looking over their shoulders versus when there's none, or it looks like you don't have support. I can speak very comfortably about my hemoglobin, or I can speak in an educational way about my numbers, and I know them. In a way, it's empowering, but it also makes me sad because why do you have to perceive me in a particular light to be given the healthcare that is my right, that I'm paying for? What are you talking about? So, it's a double-edged sword and a line of respectability politics, which is like a different conversation.

# Makeup for the Emergency Room

**Health Hats:** I remember your phone call, and when you were in Orlando, you said, I have to put makeup on to go to the emergency room. I can't tell you how much that freaked me out, but it was so upsetting.

**Fatima Muhammed-Ighile:** Yeah. They won't believe you. Human beings swear it's other people. It's not me. That doesn't work for me. It works on others. It's having to dress appropriately, make sure you smell okay, or jamming my fat fluffed finger during my pregnancy into a ring that was way too tight for me because of how I'm treated. It's different, especially in a place like Orlando, where there wasn't that kind of thing; it was just a hot mess. But yeah, I'm learning to play the game. In that sense, again, like with community building, I feel like I've gotten better at reading doctors quickly, more quickly, and they also get freaked out when you've looked them up beforehand.

Health Hats: I've experienced that too.

Fatima Muhammed-Ighile: Yeah, they don't like it per se.

### Intentional goals in life

**Health Hats:** Okay, what should we have talked about that we haven't? Thinking about that, what we're doing is following up many years after our previous conversation about this stuff. So, thinking about our listeners who are, what have you, what else do you think you've learned in managing since 2018 or 19, whenever that was?

**Fatima Muhammed-Ighile:** Two things. One, I had to. I got very clear on what I wanted in this life because my time, resources, and energy are limited. Still, sickle cell, especially at my young age, made it extremely clear that it's very limited. So, I had to be very clear about what I wanted and why. I couldn't do it all or do it all in the way I imagined before I started motherhood and being a wife. And, in terms of looking at careers and going back to school, I'm trying to be very intentional with what I do, what I put my energy into, and what I don't, hence cutting off a lot of older people from my past were rearranging people in boxes or reprioritizing what matters in my life because of the energy, time, and health. I belong to, like my husband my kids, and everything else has become secondary. And some people are not even on the map, and that's okay. And I don't feel guilty about that. It's priorities. It's not that they're wrong, evil, or mean, or it's not even about that. It's just about what is needed in the season of my life.



# You can't read my mind?



Figure 9: Image by Andrae Ricketts on UnSplash

**Fatima Muhammed-Ighile:** And the other thing I had to do is, I think, I don't know if we spoke about this when I was talking to my mom, we were talking to my mom and me. So, my mom has backed out of my care in a sense. I still talk to her and ask questions, but my husband has stepped into that role, and whereas my mom has been studying, bless God, bless him, because my mom has been studying and learning about this information for decades, and she is my mother. So, she knows me in and out and has a fantastic memory. I did and continue to put unrealistic expectations on my husband sometimes. I had to learn how to communicate to ask for what I wanted. Because I sometimes didn't know. Why am I upset for unfulfilled needs that I don't even know what the hell they are? That sounds strange.

Health Hats: No, I get it. I find the same thing with Ann. She loves and knows me, but she can't read my mind.

**Fatima Muhammed-Ighile:** Exactly. Nobody can. It's a right. It's wholly unfair at the moment, you don't know. I didn't know that's what I was doing, asking for the impossible. So again, it required me to go inward. Becoming, what do I want? What do we need? And then what? If I might want it but it's impossible, could I be okay with that? And can I get that elsewhere? So, I've joined a sickle cell support group, so I feel like I needed three new avenues to replace the one job my mom was doing.

It was a lot of emotional labor, thinking, and physical. I am utterly thankful for and appreciate it now, but I had to clarify my needs. How do you get them? It's my responsibility to get them fulfilled. It's my job to ask for it, figure out how to get it right, and put it all on one person's completely deranged.

### I'm not your caregiver. I'm your partner.

**Health Hats:** It's complicated. I think we've talked about this. There was a time, I don't know how long ago this was, but I was just being a jerk to Ann. I just knew I was short with her, and she didn't deserve it, and I didn't know why I was doing this. It's not like she did anything. I realized that sometimes I need a caregiver, and I wasn't ready to admit that to myself then. And then, I said, oh honey, I'm sorry I've been such a jerk. She got distraught with me for the first time, and she said, I am not your caregiver. I'm your partner. I had gone through all this stuff and told it in a way. It sounds like your daughter. I had no idea. I had the wrong image of everything and was just wrapped up in feeling sorry for myself. Nothing wrong with feeling sorry for myself for a few minutes. What the heck? But I don't know.

**Fatima Muhammed-Ighile:** Did you feel like you got more than what you even anticipated by having that conversation?

### End-of-life. It's for real.

**Health Hats:** Yes. Then, what came out was that we were doing our end-of-life stuff because we're old, and you do your end-of-life stuff. I was full of, whatever, I want to do it at home and she said, I'm sorry, I can't promise that. I don't know what it's going to entail. I might want to do it, but I might not be able to do it. It's sobering. What am I expecting from my family? I had some uncomfortable months; it was like, okay, that's reasonable. And that's what I love about her is she's honest about it,



**Fatima Muhammed-Ighile:** But that she can do something. You know it's for real. I love that. That's such an excellent quality to have. She'd instead tell you the truth.

**Health Hats:** I don't want her to burn herself out. Yeah. I know you don't want Azeez to burn himself out. Your kids need him. Yeah. Sometimes, it's hard not to be self-centered. I just am.

### Live below your means, cut out the noise



Figure 10: Image by Yohan Marion on UnSplash

**Fatima Muhammed-Ighile:** But even, I feel like, again, this is where I had to cut out the noise for myself. I have a disability, and even if I work, we don't know for how long or in what capacity. So, we live our lives based on one income, and we have other sources of income like real estate and other things. But I remember, one of my friends before, my ex-friend before I cut her off, she said recently, it just seems like you become so money hungry and everything's about money and investments and this, and I just, in my head, laughed so hard. Like, I laughed out loud. I was like, do you know what's at stake? Like you have a healthy body and luxury, we live beneath our means, right? This is for my kids, for my husband. So, they're not stuck, and we're not in a desperate situation.

Are you going to pay my mortgage if I cannot? No, you're not even going to be here. You'll be blowing in the wind somewhere, as you should be. So, you have no right to speak on what I don't do or how my life goes or doesn't go. I feel like once you get clarity on what you want, it's so much easier to tune out the noise and kind of laugh at it because you know your why, you know what you're doing and why you're doing what you're doing, And it did make me sad that as a friend you couldn't understand that. But again, I'm like, it's you because you won't do it. You're not going to pay my kids' school fees if needed. So, you don't get a say, but sometimes, getting that clarity can be sobering. Those difficult conversations can be tricky, like the ones I have regularly with my husband. What if I need care earlier than later, or do we have to buy these? Still, it's such a freedom to know even if we are working towards something, it doesn't necessarily go. I'll be damned if I don't look at myself and look at my kids and say that I did everything I could think of. I did my best for you physically in planning for your future. I did my best. So, if it all goes to shit, I can say, at least I can look at myself in the mirror and look at you without guilt and say that I did what I knew to do. It's hard and uncomfortable, but it's so liberating to me. I don't like lies. It's so I can't do it. It's exhausting. Because you're contouring your body and life to something that's not even true.

Health Hats: This is great. Thank you.

Fatima Muhammed-Ighile: Thank you, Danny.

### Reflection

This conversation with Fatima provides valuable insights into the challenges and personal growth of living with a chronic illness, particularly sickle cell disease. Fatima's journey highlights the importance of open communication, building a supportive community, and advocating for one's needs in various



aspects of life. Her commitment to honesty and self-advocacy serves as an inspiration for others facing similar challenges.

I will never know what it feels like to be a Muslim woman of color seeking pain relief in an ego-centered, widget processing setting. I'll never know what it feels like to be a parent of young children staring down my mortality daily. However, hearing these experiences in realtime and stories after the fact informs my consulting, advocacy, and leadership. Grateful only begins to express my feelings towards Fatima.



Figure 11: Image by Nick Fewings on UnSplash

### Podcast Outro

I host, write, edit, engineer, and produce Health Hats, the Podcast, with assistance from Kayla Nelson and three van Leeuwens, Joey, Leon, and Oscar. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band. I buy my hats at Salmagundi Boston. I'm grateful to you, who have the most critical roles as listeners, readers, and watchers. See the show notes, previous podcasts, and other resources through my website, <u>www.health-hats.com</u>, and <u>YouTube channel</u>. Please subscribe and contribute. If you like it, share it. See you around the block.

