Marty Rose - Audio.m4a

Attributed by a plus or a minus. You understand? Because those doctors don't have enough training or the consultant doesn't have enough experience of that condition, they're not going to

says you know what, this could be the reason why this person has this condition because of sickle cell.

I understand.

So, you know, you know, so sicklecell carries not just um bone corrosion; you know, you get strokes.

Yeah. Yeah.

understand it affects your blindness.

Yes.

You understand? It affects a lot of other conditions.

Okay

So, I'm going to look at how we're almost coming to the end of it now. Looking at your support system and I know that, you know, living with any chronic illness, your support system is very crucial.

Mhm

you know, when you're having a better quality of life, who or what has been your greatest source of support throughout your journey? And gone, if at all?

It's gonna sound weird, but I'll tell you.

Okay.

And then the person who partly made me was my mum. So it's about

not being ignorant but being very resilient

Um, when Mum was alive, a week wouldn't go past and say to the siblings, "Has anybody checked on Marty?"

and she probably annoys them because she'd have to, oh, Mom wants to speak to you. So that's not there anymore.

Okay.

You understand? And I'm like a gypsy, so if I'm not comfortable in any form of relationship environment, I'm out of there.

Yeah. And I don't know if I can ask this, but it's something that I have had come across a lot with many people with sickle cell.

Hmm

Obviously I know you and I know your mom played a very important role.

She did.

in your life, especially living with sickle cell. How did your siblings feel about that?

Well, one of my siblings, 'cause I'm ten years older than two of my siblings and another eighteen months older than my sibling. One of my siblings only knew about the condition 'cause I had to do a gig at the Sickle Cell and the person did a document from me and then I had to do a talk. And that was the first time

my sibling, that sibling knew what I was going through.

Not sure they did, were they understanding or...

just aware, but it's not a case of oh, I've got a firm bro, anything like that. So, I think everybody I think everybody who has a condition, Marie, I I look at it, the support is there and it's not there. So, in other words, it's not necessarily black and white, but they either understand or they don't understand the care or they don't care.

You understand, you know either when it's your sibling or your friend, they either go out and they, um, you know, I'm going to do research on it, I'm going to bring myself up to speed. If I go out with certain people or how I used to go out with certain people, I have to ask them questions such as, what condition do I have if anything happens tonight?

And then only guess what?

So they're not going to guess that I'm hearing impaired because of a brain tumor. They're not going to guess that because of the brain tumor I've got I'm unbalanced. They're not going to guess that because I'm diabetic that I can't be in a closed environment. They're not going to remember that I've got sickle cell. So those are the things you would like to tell that if an ambulance has to be called, they're aware of it.

Of course, yeah.

So, to me sometimes it's best not to go out with certain people or go out to certain places.

Yeah, I totally understand. And um look at the culture and you know the historical aspect of managing sickle cell and you know, I come from an African culture, you're from Caribbean culture. Different cultures understand and manage sickle cells very differently.

Yeah.

How do you feel your cultural background has influenced you experiencing and managing sickle cell?

Okay. A lot of my Caribbean people, especially from Jamaica, don't want to leave Jamaica to come to the UK or America or Canada, but they have to leave the country because of health reasons, because not even in a cultural background they understand the condition themselves. So then the health service is not set up to care for that part of the society.

Um, it's like I say, if you talk to my sister especially, and we're in a room and it says, "Oh, what's Marty's? Oh, Marty's got every um condition going. He's a sick one. That's it." There's nothing more, any depth.

Yes

um

explanation

explanation or they don't take it as seriously as they should.

Okay, um, were there any traditional family remedies passed down? Because I can think of a few from a Nigerian background. Were there any concoctions or things that, you know,

I don't know if you know the thing called Liquid Life. Okay, so when we were kids, like every holiday or whatever, it's fairly basic a belly wash.

Okay.

that will clear out your system, the toxins and that. That's it. Um for any other condition, everything it's got to be um uh Moringa.

Мы не говорим

uh fever grass Um, I don't know what if you know about Cersei.

Um, there's the next one.

there

yeah, and some stuff. You know, don't you? Yeah. Yeah. So everything like the bark, the saw palmetto, the leaves of the saw palmetto.

Did those help?

You know, I look at any form of remedy and medication. We need to get in our head that one hat doesn't fit all. it it it it doesn't

'Cause your body's different from my body, your mindset is different from my mindset. So, if I take sowasop, it's sort of about to take sowasop man, take sowasop. And it comes in like, um, you know when you go to the dentist and they have to numb you. And you know, anybody with sickle cell, if they're telling the truth right, we can't just go and have one needle, you know, it numbs us right. They've got to put six needles in you.

Can you feel that Mr. Pierce? So when you're coming through, you can't move, you can't talk for hours compared to other people, so do that, yeah.

Hey And well, couple of last questions. If you could speak to a young person or young people living with sickle cell today, what advice would you give them?

Um, make sure that your siblings are aboard, make sure that your friends are aboard.

educate your parents or parents. Um if you go to school, make your teachers aware of it. The head teachers are aware of it. It gets support. Um make sure that you're hydrated. Uh explain to the teachers or your friends why you have to keep going to um the toilet and so forth. Um just make sure to educate yourself, educate the people around you. That's also, you know, to make themselves aware of it.

Um, don't look for sympathy, look for empathy. There's a difference. Um, if you get the empathy side of it, then they're more likely to be okay. We're not going to treat you, don't want to be treated anything different, but his condition comes with conditions. Does that make sense? Yes.

And uh, what changes would you like to see in the future for people living with sickle cell?

It's not just because you, uh, especially in the UK that we can only talk about that the treatment still goes on as if you're a child going to adulthood. In fact, when you get into adulthood, we need treatment as much as the child needs it. Um, so, I think we need to come, we have to keep the awareness going, but the support has to come with the awareness. It has to come strong, it has to be consistent in the support. It hasn't got to be, oh, this person has sickle cell.

That person has sickle cell, uh thalassemia. That person's got both, both conditions. We've got to treat them differently.

Um, we've got to fit the support for that condition, for that person who's got that condition, and make it consistent.

We've got two more questions and one of them is how has sickle cell affected your mental health? Looking back and now.

I think back then because I didn't know what was going on, I didn't know what a crisis was. I didn't know why at a certain time of the season, why especially winter, you know, why I felt the cold more than others and I couldn't handle it and I have to be warm all the time. I can't rem- I can't understand when it comes to summer, if it's really summer and there's no um...

Well, it depends what part of the environment you are. I don't know if you get it as well, Marie, where you find breathing can be harder.

Yeah, so that's what I have. So when it's really hot and there's no breeze, I can't go out.

Okay.

I have to stay in

How does that make you feel?

It's a bit like when I came from church and the weather was nice as compared to today. Everything's so bloody ridiculous and I said I'm going home to work. You know what I mean?

Yeah

Oh, watch F1 today, you know what I mean? That or watch football today, that's it. But I'm sort of

used to it.

But I'm I'm I'm really I'm really proud to be doing this interview with you because you are such a positive person. I mean, you've got sickle cell, you've got multiple complications, but your approach towards a lot of things, not just about sickle cell, a lot of things in life is quite positive.

Yeah, I think it's a really good example for the younger generation to really see that, you know, yes you're born with this, but you've got to accept it like you said, and just get on with life.

Yeah, you got you got you got to make anything in life work for you. You know, um it's not easy 'cause what people don't realize that

Positive can't work without negative, negative can't work without positive, right and wrong can't work without each other. It's about working with them.

Yes.

So take the negative and make it into a positive.

Thanks makes absolute sense. How do you feel about sharing your story today as part of this project?

I think it should help people. It should make people stay positive. Um it should make people aware that, you know, you can still do things. It's challenging.

I'm not gonna lie, it's challenging. Um, like I told somebody in church yesterday, block out what you need to block out and surround yourself with the people you need to surround yourself with.

and that's the best advice I could give to people.

Thank you so much. Thank you. We've come to the end of the interview. Do you have any questions, anything you want to highlight or anything you want to ask me?

Um, the only thing I would say is keep doing what you're doing. Keep pushing awareness.

It could be tough because not every ear is going to be open, not every eye is going to be open to see. Um, and it's going to be challenging, which I know you're going to know. But life is a challenge and look at every ups and every down as a season.

There's a season for everything, so you'll have today. We're having spring today. But look outside, it doesn't look like spring. And we're going to have summer and it's going to be shining. We're going to have autumn, bitter dip. Uh, and we're going to have winter. In all those seasons, make the best of it. Take each season as it is. And not make winter be autumn or summer to be spring. Just adapt.

Thank you so much. That's a beautiful end to this interview and I really appreciate your time, Martin. Thank you.

Okay

Good This was amazing.

Okay.

Thank you.

I didn't bore you ladies, did I?

No, sorry, I couldn't, I couldn't stop to get you guys to answer. I think it was easier to flow with one person.

So, is there anything that you've learned?

is an inspiration. I mean, when I got to meet you the first time, I thought I was in a very bad place.

Yeah, it was. I can remember.

Yes, I'm sure you can.

she wasn't she wasn't um I don't think at first she was uh not the word friendly you was aware I could tell you had a lot going on.

had a lot going on and it's because of the way I've been treated for so many years.

exactly

I can't remember who told me about the center and I thought one day I'll just walk in and see, you know, is he going to be one of the others that are coming and they just ignore you and just say, oh yeah, she's got sickle cell, let's sit over there.

Yeah, because yeah, when you came to the center, I don't know if you were there on time and it was full.

full

Right, so say for instance we had peace. Right over there. We had, um, if you're over there, we had you over there, right. And I and I just got mad. And I just said to... you knock you knock the table. I say, listen. I say, you sitting over there, I'm not going to learn about how you handle your condition. You see, you know what I mean? And we just got everybody to put their tables together. And it was just a tradition on a Thursday that all of us sat together, ate together, and there were no clicks.