Albertine and Maureen.wav

Sickle Cell Disease: A Multigenerational Journey of Resilience and Care

Transcripts

Speaker 0 Albertine Kamba (Mother): Shared her lifelong experience managing sickle cell disease across Congo, France, and the UK. She emphasised the critical importance of self-advocacy, the necessity of understanding one's own body, and the vital role of community support. She expressed concern regarding the decline in specialised NHS services and the lack of structured support for young adults transitioning from paediatric care.

Speaker 1 (Interviewer): Facilitated the session on behalf of the "Sickle Cell Stories: Then and Now" project. The interviewer focused on documenting the evolution of care, the challenges of the transition to adult services, and the unique perspective of a household where both mother and daughter live with the condition.

Speaker 2 (Maureen Daughter to Albertine): Provided a candid account of growing up with sickle cell, highlighting the social isolation and physical toll of the disease. She expressed frustration with the lack of educational and career support for young adults and noted that while she is grateful for the medical care received, she struggles with the transition to adult services and the invasive nature of some hospital procedures.

Key Points And Decisions

Care Disparities: There was a consensus that while the UK healthcare system provided more support than previous experiences in France or Africa, recent reductions in specialised community nursing services have negatively impacted patient quality of life.

Transition Challenges: Both speakers identified the transition from paediatric to adult care as a significant gap in the current system, noting that young adults often feel abandoned once they age out of children's services.

Self-Management and Lifestyle: Both speakers agreed that proactive self-management—including medication adherence, diet, and recognising early warning signs of a crisis—is essential for survival and maintaining a degree of normalcy.

Social and Professional Needs: The participants agreed that the current healthcare model focuses heavily on acute medical intervention but fails to address the social, educational, and professional development needs of young people living with sickle cell.

Next Steps

Speaker 0 (Mother): Committed to continuing her role as a primary support for her daughter while advocating for the development of community-based programs that offer training and social opportunities for young sickle cell patients.

Speaker 1 (Interviewer): Committed to documenting these testimonies to ensure that the lived experiences of patients are preserved and used to advocate for improved, holistic care within the NHS.

Speaker 2 (Maureen): Committed to focusing on her personal development, specifically in computer skills and education, while continuing to manage her health proactively and seeking ways to build a social network despite the limitations imposed by her condition.

SPEAKER_0
[00:00:00,151]Um, I agree.

SPEAKER_1
[00:00:03,151]Hello, uh Maureen.

SPEAKER_0
[00:00:05,451]I'm Joey. Um let's get right into it, okay?

SPEAKER_1
[00:00:09,091]So you were born in Africa but have grown up here in the UK with sickle cell. What has the journey been like and has the NHS given you what you needed?

SPEAKER_0
[00:00:22,871]Sorry.

SPEAKER_0
[00:00:28,921]Okay Oh dear.

SPEAKER_1
[00:00:30,771]Okay.

SPEAKER_0
[00:00:33,241]No, es esta.

SPEAKER_1
[00:00:35,141]It's not true. Alright, so you were born here, you were born in France, but have grown up in the UK with sickle cell. What has the journey been like and has the NHS given you what you needed?

SPEAKER_2
[00:00:49,501]Well, the journey was very difficult. I didn't exactly um mix with my classmates. Um it wasn't easy for me to make friends or socialize with those people even in class. It was difficult. And most of my life in the hospital she was hospitalized.

SPEAKER_2
[00:01:16,861]For me, my life was just home and hospital school. School was just part-time for me. Was very hard to socialize with people even if I do try to make friends, it wouldn't last long.

SPEAKER_2
[00:01:32,191]I don't usually make long conversation with them because I don't exactly know how to make long conversation with people. I they learn I never had friend before. And most of the friends that I have then at uh made my life was hospital friend bed friends. And in school was just so difficult so.

SPEAKER_1
[00:01:57,451]Thank you. Okay

SPEAKER_1
[00:02:00,741]So your mom also has sickle cell as we know. And what has it been like growing up with someone in your home who understands exactly what you're going through?

SPEAKER_2
[00:02:14,071]Well, it was helpful. very helpful. Uh, my mom with her sickle cell, she managed to know how to control it.

SPEAKER_2
[00:02:26,251]me, I was very young when we watched this as start as I have been feeling lots of different emotions, you know. Different questions has been coming to me, infections. And my mom has learned how to control the sickle cells. So when I see my mom strong, even if she is sickle cell, it does give me lots of energy, you know. Even if I'm sick, I wake up one day again and just start over again, so yeah.

SPEAKER_1
[00:02:57,781]That's very good to know. So your mom has been some inspiration to you.

SPEAKER_0
[00:03:02,921]It's really good.

SPEAKER_1
[00:03:04,771]So what did you wish the world understood most about what it's actually like to be a young woman living with sickle cell right now?

SPEAKER_2
[00:03:17,491]That's hot. I've never asked myself this question before, so I don't exactly know how to answer that.

SPEAKER_2
[00:03:25,191]Yeah, exactly, I understand that because no one can exactly know how we feel exactly. And it's hard to exactly tell to the whole world how we felt, especially if you don't know ourselves and we can't exactly help ourselves with that. So, we just need to live with it.

SPEAKER_0
[00:03:45,681]Yeah.

SPEAKER_1
[00:03:46,611]So knowing that there are charities like Plasma doing the work they're doing, advocating and providing support, is one of the ways that the world out there can support you. How has that been for you?

SPEAKER_2
[00:04:01,841]Well, my only support was my mom, obviously. And the school wasn't exactly supportive, even if I was sick. They were always putting lots of pressure on me. But some people have been very helpful too, so I'm glad I'm very grateful for that. So, I am content.

SPEAKER_1
[00:04:25,411]to wish there are more charities like Plasma who are making a lot of noise for

people to know about the disease and to understand and provide support for people like you.

SPEAKER_2
[00:04:36,871]It would be great if we could provide support for education because some people like me miss lots of education, you know. So it would be great if we could support that. Help... help...

SPEAKER_1
[00:04:52,051]Okay. We're moving on but like I said, just take your time to answer your questions in your own time. All right, so we're going to go on about your growing up. Uh, what is your earliest memories of you knowing that you had sickle cell? What do you remember?

SPEAKER_0
[00:05:10,111]Um.

SPEAKER_2
[00:05:12,001]I would say it was the day when I was with my father. Yeah, we went to to an amusement park. We came back late night and my father had a really big fight with his wife. It was lots of emotion for one night. I was, I think I was six. I don't remember how old I was, four, six at this day. And my father and his wife had a big fight. It was lots of emotion.

SPEAKER_2
[00:05:45,931]I was young.

SPEAKER_2
[00:05:46,981]and with all this emotion I started to feel strange like I was starting to vomit, I was my body was trembling everything and I wake up myself in the hospital like uh for my age five years old being in a hospital where I using what a hospital is, where the nurses around me, me having blood tests done and everything, me beginning pain, feeling the pain for the first time. I started to realize that I was I need to check my blood pressure sometimes because I was having crisis for the first time.

SPEAKER_2
[00:06:27,031]even if I didn't know what it was, that for the first time I started to feel pain in my spine.

SPEAKER_1
[00:06:36,811]So, did you know when you were born? Has it ever felt like a part of your story as you were growing up that you had sickle cell?

SPEAKER_2
[00:06:50,001]Well, when I was born, I was a baby. I had a sickle cell since I was born. I can exactly tell when I was sick, well, if I could feel the pain. Since that day that it happened, since the first time that I realized that that pain when I started to amplify the pain inside of me, I started to realize that I was sickle cell. So yeah, and started to live with it. At first, it was very scary.

SPEAKER_2
[00:07:22,401]I was I was so afraid. It's like I couldn't breathe anymore. So, yeah.

SPEAKER_1
[00:07:28,221]Was that at the age of six when you went to that amusement park that was the beginning for you?

SPEAKER_2
[00:07:33,491]That was the beginning.

SPEAKER_1
[00:07:34,941]Okay. Alright. So, what was school like growing up with sickle cell here in the UK?

SPEAKER_2
[00:07:42,811]Here in UK, school was very easy, much more comfortable than school in France. So, lots of people was helping to here. Most of the people here was helping me here. And I managed to make friends too, so

SPEAKER_1
[00:08:02,521]But what if you called him France?

SPEAKER_2
[00:08:06,041]The difficulty in fact is that the teacher didn't care that I was sick. So they weren't supporting that the teacher here in Uganda. Even if I was sleeping, always complaining, they were always saying to me that I'm going nowhere, that I'm not going nowhere in my life, that I wouldn't make it in my life. So here they are very supporting. Whatever I choose to do, they are supporting.

SPEAKER_2
[00:08:36,231]Even if I'm sick, they always see, uh, the person to send me some homework and in the hospitals so that I can so that I will not be left out so.

SPEAKER_0
[00:08:46,811]Yeah.

SPEAKER_1
[00:08:47,721]Did you feel that they were ignorant of the sickle cell disease or do you think it was a personal thing that did you think that they didn't know what sickle cell was and how to help you in France?

SPEAKER_2
[00:09:01,821]I think they didn't know exactly what sickle cell was, or I don't know, maybe it was personal because I was the only one in my class who was all has the same accent and sake. I don't know exactly.

SPEAKER_1
[00:09:18,411]Oh yeah. So compared to France, you receive more support here in the UK than in France, which was quite helpful, wasn't it? Okay.

SPEAKER_1
[00:09:31,721]How did having a mum who also had sickle cell affect how you understood your own condition?

SPEAKER_2
[00:09:41,061]Well, one time I remember my when I was eight, yes, my mother fell ill, I, She was sick. We were all sleeping in the living room.

SPEAKER_2
[00:09:54,311]I was awake because I was sleepy. I was playing games. And I went to see my mom once in a little while when she was asleep. She was she wasn't waking up, so I was worried.

SPEAKER_2
[00:10:08,171]And the first time I I call my brother, I call my brother because my mom wasn't waking up, she was swimming out and everything. And when she mom she went to the ambulance, I realized um, well, well, I need to be prepared, you know, with my sickle cell. When I need to be prepared with my sickle cell, this kind of thing can happen to me. And then after that, my life, last my sickle cell started to change. I've been having infection. My arms had been started to swell, my legs had been started to swell, so yeah.

SPEAKER_0
[00:10:47,121]C

SPEAKER_1
[00:10:48,181]Okay, so when you saw your mom in crisis, were you scared?

SPEAKER_2
[00:10:55,551]I was scared. Salut.

SPEAKER_1
[00:10:57,911]Did it make you feel like your own condition was gonna get worse or you can push through?

SPEAKER_2
[00:11:03,941]Uh, I don't exactly remember what I did that day, I won't say. I do remember what happened. I do remember what happened, how it happened, and at first I thought it was my fault because I woke up my mom in the middle of the night. You know, unfortunately she was sick because of me. But when when my mom was starting to heal after we leave, but I did feel bad in a way. I know if my body started to feel pain at that time, I don't remember exactly.

SPEAKER_0
[00:11:39,551]No.

SPEAKER_1
[00:11:41,231]Thank you for that.

SPEAKER_1
[00:11:42,801]Okay, the next set of questions is about your care. Also, we still want you to take your time, break it down. If there's anything you don't want to answer, just escape and we'll carry on, okay?

SPEAKER_1
[00:11:53,981]Alright, so how has the NHS looked after you since you came here? Have there been any good experiences or bad ones? Which ones really stand out for you? Can you briefly tell me about your experience with the NHS?

SPEAKER_2
[00:12:10,471]NHS mean like the hospital?

SPEAKER_1
[00:12:13,051]Yes.

SPEAKER_2
[00:12:13,971]since uh, well, I had good and bad experiences, I would say both. Yes, and I would say the bad part was when they were trying to take a cannula in. Yeah. Because I'm difficult to

cannulate and my blood flow very deep and I had a bad experience in the hospital. Like, I had six or five nurses or one more trying to plant a cannula inside. It was like a torture.

SPEAKER_2
[00:12:50,791]the thing that um that stood out for me in the NHS is that they were even if I was in pain, they were always there for me, they were helping me.

SPEAKER_2
[00:13:05,461]I have lost nurses that that know names, even the nurses when I was five years old, they are still here today. Yeah, they remember me, I remember them. So, yeah.

SPEAKER_2
[00:13:18,891]It's like family, you know. We're like a family, so I know all of them, all the nurses at the hospital, I know them. And they're very, very helpful to me.

SPEAKER_1
[00:13:30,171]Okay.

SPEAKER_1
[00:13:31,061]that's really good to hear 'cause our next question has to do with how the nurses or the team at the hospital relate to you. If any of them has ever made you feel like they did not believe in your pain or did not take you seriously, have you ever had that experience?

SPEAKER_1
[00:13:50,021]As far as you can remember.

SPEAKER_2
[00:13:54,981]What'd you say?

SPEAKER_2
[00:13:58,481]When we're sick, we don't pretend, you know? We don't pretend when we're sick. We know when we're sick, we call the nurse. We know the nurse are busy, so even if we call the nurse multiple times, I do get the...

SPEAKER_2
[00:14:13,001]Welcome. They stay calm even if it is annoying that they stay calm. So yeah.

SPEAKER_1
[00:14:18,491]Москва Let's do this. one of the lucky ones. Hello

SPEAKER_1
[00:14:23,951]So, what do you do when you have pain in crisis, immediately it starts, what actually helps you before the NHS or the hospital intervenes? What do you do for yourself?

SPEAKER_2
[00:14:39,151]Well, before, uh, it was hard to

SPEAKER_2
[00:14:45,421]uh I didn't have anything before, but then I started to have like some herbal tea machine to help me to breathe. This helped me a lot. And I have medication at home that I take, but some of the time it doesn't last long, it just lasts for a few days, so

SPEAKER_1

[00:15:06,111]Okay. Right, so Do you have any personal lifestyle that you think helps prevent a crisis? Like diet, exercise?

SPEAKER_2
[00:15:19,181]Yeah, exercise, like I can't run anymore. My legs are are too heavy, I'd say. Since I since I had an infection in my knees. Yes, in my knees. I've been in a wheelchair for like five months. Yes, five months. And since then, I haven't been exercising my knees and everything. So I can't exactly pretty much run like I did when I was a kid. All the time when I run, I probably my ankles, my back, so yeah.

SPEAKER_1
[00:15:56,151]Are there any foods or stuff that you avoid because you know that might trigger your crisis?

SPEAKER_2
[00:16:03,331]Wow.

SPEAKER_2
[00:16:04,601]No, I don't worry about food. So I do not eat some foods right now because my stomach, I have very bad stomach indigestion. It gives me crises all the time, so I do avoid some of the food.

SPEAKER_1
[00:16:21,291]Okay.

SPEAKER_0
[00:16:22,951]Right.

SPEAKER_1
[00:16:25,131]Good to know.

SPEAKER_1
[00:16:26,751]Right, so last one on your care, um did moving from children's services to adult care feel supported or did it feel like you're being dropped as your care continued the same way since you were a child? Since you moved from child services to adult services, how has the care been?

SPEAKER_2
[00:16:48,771]Well it's different. It is different but it's still the same. satisfied is the pen it's still the same, I would say.

SPEAKER_1
[00:16:58,101]What what are the differences could you tell us?

SPEAKER_2
[00:17:01,001]world

SPEAKER_2
[00:17:03,511]Childcare when I was in childcare with the nurses, uh, was more, there were more nurses around me, you know, helping me. Yeah, and there was my mum too there. My mum would come and sleep at the hospital with me. But the adults side, there's less nurses, you know, because the adults just give us medication and they let us sleep. But that's the good part. They're here but they're not fully here and they're not beside us.

SPEAKER_1
[00:17:43,801]All right, but the level of care, are you are you satisfied with it?

SPEAKER_2
[00:17:48,611]Yes, I'm satisfied. Either way, both sides are satisfied.

SPEAKER_1
[00:17:52,491]Yeah. Thank you, Marie. So we're going to move on to questions about you and your mom.

SPEAKER_1
[00:18:00,281]Also feel free, say what you want to say. You can keep it brief or you can elaborate, whichever way, but don't hold back. If you don't want to answer again, just skip, okay?

SPEAKER_0
[00:18:16,501]Alright.

SPEAKER_1
[00:18:18,761]So for you and your mom, what has it been like watching your mom live with sickle cell alongside you? I know we've talked about that from the beginning, but what has it really been like?

SPEAKER_2
[00:18:35,831]Well, um, my mom, she has sickle cell, but in she always been telling me that even if she has sickle cell, she always managed to, you know, do stuff in her own ways, slowly. And she always told me, "Molly, you know, you have sickle cell. You need to manage yourself. You need to manage your medication. You need to manage, you need to know what you can and you need to know what you can't do."

SPEAKER_2
[00:19:10,281]don't follow your siblings, just step by step, you know, take your time, so. Thanks.

SPEAKER_0
[00:19:19,251]Hey

SPEAKER_1
[00:19:20,361]Is there any particular advice your niece gives you about managing your condition that has really helped you?

SPEAKER_2
[00:19:28,821]communication

SPEAKER_1
[00:19:30,081]Keep on top of your medication. Nothing else.

SPEAKER_2
[00:19:35,741]one

SPEAKER_2
[00:19:39,261]That's the last that I can think of at the moment. Can't think of anything else.

SPEAKER_1

[00:19:45,791]white But do you and your mom openly talk about sickle cell or do you tend to keep things to yourself and rather not talk about it?

SPEAKER_2
[00:19:54,221]We talk about it when I want to do stuff like with my siblings. Like I want to go outside party or to follow my sister when she goes out with my cousin. My mom told me that Molly, you know, you can't do you can't do this. You you don't follow your siblings with your condition. You need to you need to be careful, you know, don't follow your siblings, you know, when she says don't stop. It's gonna be annoying, but I do get it in a way.

SPEAKER_1
[00:20:32,551]He's just looking out for you. Yes. That's good. So, we're going to move on now to your life now and the future.

SPEAKER_1
[00:20:43,891]So how does sickle cell affect your day-to-day life?

SPEAKER_2
[00:20:49,771]I can barely move, you know, walking as I say, walking, even going to cities, it's very tiring for me. No, I would say physically, it's complicated. My body, all this, all the pain that I have in my life has been tearing my body, you know. I can barely walk for for miles without having breaths, you know, without catching my breaths, you know, or without having back pain.

SPEAKER_2
[00:21:25,361]So, it's difficult.

SPEAKER_2
[00:21:27,451]But it's fine. I do organize myself some visual exercise for helping my body to reshape again, you know, to be energetic again. So, yeah.

SPEAKER_1
[00:21:42,791]So, is that when you're in crisis or um outside of crisis like today, what do you try to make the most of it when you feel okay?

SPEAKER_1
[00:21:56,461]How do you feel?

SPEAKER_2
[00:21:59,011]that's complicated because I don't know. Most of it I'm trying when I'm here, I'm trying to exercise my body, you know, to reshape it so that I can go outside by myself some something to do. So kind of hobby, some kind of uh yes, starting over, you know, going back to school so that I can be prepared for next year, going back to school, learning classes and everything.

SPEAKER_1
[00:22:31,431]So just off the uh plane. How often do you get crisis in a week and a month?

SPEAKER_2
[00:22:39,431]How's it going? Allez, calmez-vous, s'il vous plaît.

SPEAKER_1
[00:22:42,081]average

SPEAKER_2
[00:22:43,591]I can't exactly say a month, once in a month I would say.

SPEAKER_2
[00:22:49,871]two minutes after I was I say hello hello. My my process is so predictable, it just comes and goes.

SPEAKER_1
[00:22:59,211]Okay, so how long is the hospital stay?

SPEAKER_2
[00:23:02,541]Well, I guess it's been about one week or two weeks, I'd say.

SPEAKER_1
[00:23:07,911]One week, two weeks, every month. That's a lot. Alright, so has it affected how you think about your future, your career?

SPEAKER_1
[00:23:18,491]relationship and having a family yourself. Have you thought that far?

SPEAKER_2
[00:23:23,551]Não, é, não. for the work for working yes I

SPEAKER_1
[00:23:31,241]I've thought about work.

SPEAKER_2
[00:23:32,451]Yes, because after a year, I still don't know what I can job I'm going to do, so. But, um, but now when I... for work, I'm more concentrating in computers and more relationship, I would say more friendship, you know, since today I still don't know how to communicate with people or make friends, so. Well, this is the part I think it's this of what's most scary of finding friends, building a relationship. I wouldn't know how to do that yet.

SPEAKER_1
[00:24:06,671]not to go far off thinking of a family of your own.

SPEAKER_2
[00:24:12,371]Không, không phải đâu, không phải đâu, sao rồi? Không phải đâu, không phải đâu, sao rồi?

SPEAKER_1
[00:24:15,511]Somewhere in the distant future. See what happens.

SPEAKER_2
[00:24:18,491]Yeah, no, right now in the future, I want to go on vacation and see the world and...

SPEAKER_2
[00:24:28,391]Yeah, I'm not enjoying it yet. Somewhere in the mid-coast. Maybe even a poolside.

SPEAKER_1
[00:24:36,311]Okay, you might have been seeing anything, you never know. Anyway. So, what would you change about sickle cell care if you could change one thing?

SPEAKER_2
[00:24:47,571]Está em ponto de vir, né?

SPEAKER_1
[00:24:51,371]In regards to your care, what is it that happens at the hospital that you think you wish they wouldn't do or you would like for them to change the way they do it?

SPEAKER_2
[00:25:02,101]I would like them to stop to pour cayenne on me.

SPEAKER_0
[00:25:07,011]No, it's not working.

SPEAKER_2
[00:25:09,441]the time when they tried to cannulate me, they they do realize that it's not working, there's no blood coming out, but they still insist. I want them to stop, just give me medication tablets, I don't know, but stop cannulating me.

SPEAKER_1
[00:25:23,701]Have you ever mentioned it to them before?

SPEAKER_2
[00:25:26,201]Yes

SPEAKER_1
[00:25:27,411]a lot of times. And what's their reason why they always have to put canola?

SPEAKER_2
[00:25:32,081]Well, because with me with my infection, with my sickle cell, with the infection I come, I guess when it was time, I have infection all the time, so all the time when I have infection I need to have different antibiotic coming. So, and in my infection it's blood and needs to be... Put through the vein.

SPEAKER_2
[00:25:54,361]I'm in the vents.

SPEAKER_1
[00:25:55,601]Yeah Right. So what would you say to another young person who has just been diagnosed with sickle cell?

SPEAKER_1
[00:26:09,841]If you meet a young person like you who's gone through life a bit, they've been sick on and off but they're not aware that it's sickle cell, and then all of a sudden they realize it's sickle cell, what would you tell them from your experience?

SPEAKER_2
[00:26:27,381]I would say it's gonna be okay. You know, there's nothing to be afraid. It's so all you, you gotta, you gotta learn how to to control it, how to feel it and either way, he's gonna stay with you, so you might as well just deal with it. There's nothing to be afraid of.

SPEAKER_2
[00:26:50,131]That's why I'm going to be a president.

SPEAKER_1
[00:26:53,931]Thank you so much. that's very brave and that's inspiring for a lot of people. Thank you for your time and thank you for doing this interview.

SPEAKER_2
[00:27:04,331]Thank you.

SPEAKER_1
[00:27:05,431]Thank you.

SPEAKER_0
[00:27:06,311]Ну, молодец. Yeah. Wow. You look like Bill. That's fantastic.

SPEAKER_1
[00:27:14,391]That's fantastic! Well done!

SPEAKER_0
[00:27:23,591]Really? But you did so you did so well, honestly.

SPEAKER_1
[00:27:27,251]Wherever I went, you were straight on.

SPEAKER_0
[00:27:30,841]Worrying that's what you were just saying. But it's okay.

SPEAKER_1
[00:27:33,411]No, no, no, she was, no, she was... She was very shy person. I can't talk to people. Well, you just sound dumb yourself. Look at you, you're literally looking at it. You were, you were, you were like a professional. Yeah, that's good. Amazing. Thank you. Thank you. Yeah, relax now. Relax now. Relax now. Relax now. Relax now.

SPEAKER_0
[00:28:03,091]I really did well. Yeah. Very cool.

SPEAKER_1
[00:28:09,251]Okay.

SPEAKER_0
[00:28:10,711]That's what we do this weekend. Enter D'accord. Tu veux que je te coupe ? C'est pas ça, c'est du Coca. Да не говори так. ayayaya Heh.

SPEAKER_0
[00:28:42,331]Do you know I have glasses? So maybe secondhand seller. Your time. Do your best.

SPEAKER_0
[00:29:05,811]Sorry, I just need to tell my colleague. Не надо так громко.

SPEAKER_1
[00:29:16,701]We're not ready.

SPEAKER_1
[00:30:12,211]Ready?

SPEAKER_0
[00:30:13,591]Okay

SPEAKER_0
[00:30:24,721]Maybe we want to turn this off a little. Oh. It's okay, it's normal. I was feeling... It's lower, it's lower. I was thinking it was... I was feeling... It was quite low. Yeah.

SPEAKER_0
[00:30:35,681]Я тебе кушать можно? OK, full air. Pas besoin qu'on me la donne moi. Tu dis de descendre.

SPEAKER_0
[00:30:44,141]Après, elle va descendre, première partie. D'accord ?

SPEAKER_1
[00:30:51,981]And is this how you're going to sit throughout?

SPEAKER_0
[00:30:54,851]Да, гонорар.너 닮은 거야

SPEAKER_1
[00:30:58,341]No, it's okay. I just want to position this.

SPEAKER_1
[00:31:04,681]Like you're sitting in your comfortable way.

SPEAKER_0
[00:31:07,981]Ja, aber das ist doch It depends on the question.

SPEAKER_0
[00:31:14,411]I don't know. Okay, okay.

SPEAKER_1
[00:31:16,511]Okay. All right, that's that. Hello, Abhay.

SPEAKER_0
[00:31:21,591]Hello.

SPEAKER_1
[00:31:22,441]You good today?

SPEAKER_0
[00:31:23,741]Yes, we're good with that.

SPEAKER_1
[00:31:25,461]yowai

SPEAKER_1
[00:31:26,161]So this interview is on behalf of Plus Smile of Hope and our project on Sickle Cell Stories. Then and now, which is supported by the National Lottery Heritage Fund. So the project is about capturing real stories, like I said before, from real people who have lived with sickle cell disease. So we can document how care has changed over the years.

SPEAKER_1
[00:31:52,661]and make sure those experiences are not forgotten. So your story is particularly special to us because you have lived with sickle cell from France and now here in the UK, and you have also raised a daughter living with the same condition. So that gives us a perspective that is very rare because we we rarely get two people in the same household with sickle cell. Yeah.

SPEAKER_1
[00:32:22,771]So, um, again, there are no wrong or right answers, and just speak naturally in your own words. You can pause, you can skip, you can take your time, whatever you're comfortable with, okay? And then we can stop altogether if you need a break, and you're all in control here. Okay. So, we'll start with three short questions for the recording and normally we expect the answers to be two minutes, but don't worry if you have more than two minutes, you can you can speak, okay?

SPEAKER_1
[00:33:00,291]So firstly, you have lived with sickle cell disease your whole life. First in Africa, then here in the UK. I think at some point in France as well. Yeah. How has the care been different? Which system has saved you better?

SPEAKER_0
[00:33:19,521]um, when I left Congo, I was 20. Grew up in France, all my education, and I was uh with my crisis, you know, like a whole like sickness situation. And I was going to the hospital in France frequently, and they they knew the condition. They knew the sickness, how to control, how to take care. So I learned everything in Paris.

SPEAKER_0
[00:33:57,411]how to manage step by step when I was like 14, 15, 19 until when I was an adult. And when I went as well and met my husband, create my family. The thing is, all my life I have to cope with this situation. When I was on the crisis, everything was stopped.

SPEAKER_0
[00:34:27,801]And my family, when I say family, my mom and my dad with my six siblings. Uh, we was six, four boys and two girls. Me and my sister single sons and four boys, no, just uh half. So, in the house, it wasn't like a utopic.

SPEAKER_0
[00:34:55,231]Because I saw some family that was like, uh, there was hiding, uh, my kid has sickle cells and things like that. But in my house, my dad would say, okay, so Arby, when you are sick, you are sick.

SPEAKER_0
[00:35:11,471]Don't stress. We're going to just do everything at home and my brother, my four sibling, they was doing the things at home. Me and my sister, when we were safe, we was doing nothing.

SPEAKER_0
[00:35:27,491]No sport, no swimming pool, no something like that was vanished. Even when, even in school, we have like a fitness, no sports something like that. So, step by step, my my doctor, he teach us how to behave when I was young, when I become a woman. Okay, did you ask, did you explain your boyfriend so you have this. Step by step.

SPEAKER_0

[00:36:02,061]some

SPEAKER_0
[00:36:03,951]I was very helpful, comfortable with this. When they showed me how to manage my life. And I told myself it was very peace. So, all the things was for me when I had Morin. Even my friend, family, they was like, "Ah, Morin she's sick and stuff."

SPEAKER_0
[00:36:31,431]I said, hey! I'm not afraid. I know because I'm I'm single sense. So I know the way. So I'm gonna help her. That's not a problem. It wasn't a problem for me even for my mom or my dad.

SPEAKER_0
[00:36:46,371]So we got like this and step by step, but Marine when she was diagnostic, the doctor in Paris told me, okay, usually the price will come at one year.

SPEAKER_0
[00:37:02,691]Moin, start the price at maybe eighty-nine, something like that. BBC don't know exactly.

SPEAKER_0
[00:37:11,131]she was just screaming and so we take off moringa. I was learning moringa from the things when moringa was sick, I had to manage myself.

SPEAKER_0
[00:37:24,611]I don't have to be sick as well. So the doctor was doing the same more research, we too would have to do some, so I have to be there like that all the time.

SPEAKER_0
[00:37:36,131]and uh step by step, you know, we it wasn't okay every day.

SPEAKER_0
[00:37:44,291]but when it was very difficult, I would just let like my mum or my friend hug me and me get rest. something like that.

SPEAKER_1
[00:37:55,141]Okay. So the main question was, um, has there been any difference in the care system you received in the UK compared to out there?

SPEAKER_0
[00:38:05,781]Yes, very different. uhm a lot of there's no the I will say the the care is not the same.

SPEAKER_0
[00:38:21,011]The not a lot of hospital know exactly how to do with sickle cell patients.

SPEAKER_0
[00:38:29,341]Even I was in Paris, just the hospital when I was going going know how to deal. I don't have to go to another hospital in another city country something like that. Or but here was better. And when I use

SPEAKER_0
[00:38:50,681]when I have the opportunity to come here for my walk, I would I would like to say

no. But when I spoke to Morine Doctor, I told Morine Doctor, uh, I have a bigger opportunity to go to London but I think I'm gonna refuse. She said, why? And Morine, she said, because first time I'm sick of self, my life is finished.

SPEAKER_0
[00:39:15,551]The doctor told me, oh, no, I better. We was all, all the training she had, she was coming here. She told me, no, go.

SPEAKER_0
[00:39:27,971]That should give me a big hope. Okay. The doctor marine was like a two, yeah two years or three years old.

SPEAKER_0
[00:39:37,991]She told me, okay, when you go, check the hospital, check the service, be aware.

SPEAKER_0
[00:39:46,871]All the time when you go do that, slowly slowly, and when you're ready, just let me know. I will prepare all the documents for moving. That was wonderful.

SPEAKER_0
[00:40:00,691]It's like something was opened big like this for me, like a new life, something will be possible for me. C'est pas vrai que tu fais ça.

SPEAKER_1
[00:40:09,831]That's that's fantastic to hear, isn't it? Yeah. Okay.

SPEAKER_1
[00:40:14,491]So when you found out your daughter also had sickle cell, what went through your mind and how has it felt to watch her grow up with the same condition you lived with?

SPEAKER_0
[00:40:25,871]Bon. Euh, I wasn't like happy, non, parce que euh, me, I have my personality, Moïse il a le sien. So, I know it will be difficult, but uh, have to be prepared.

SPEAKER_0
[00:40:43,971]So I prepared my mind. even it's going to be difficult. It was difficult because Marine she was all the time infection, infection. Every month she was in hospital.

SPEAKER_0
[00:40:56,451]slowly. Even when we move here. We came here when he was four years old.

SPEAKER_1
[00:41:02,601]Okay.

SPEAKER_0
[00:41:03,161]She was in reception and she did all the servicing works while hospital kids, young and adult. Every month she was in hospital. It was cold. It was very difficult.

SPEAKER_0
[00:41:18,161]But the service, I have a lot of support all around me, even for me who has sickle cell as well.

SPEAKER_0

[00:41:28,321]So, I'm not complaining. I don't regret because they helped me a lot. More if I would stay in Paris. It wasn't.

SPEAKER_0
[00:41:41,631]exactly

SPEAKER_0
[00:41:44,891]Wait, sorry. Because you were looking at this thing, it made me to think about something. I just need to play that, make sure the volume is coming out.

SPEAKER_0
[00:41:54,691]Okay. Okay.

SPEAKER_1
[00:41:56,831]Hello

SPEAKER_0
[00:41:58,061]Take care. Sorry. Nope.

SPEAKER_1
[00:42:08,371]Okay. So, after everything you've been through, what do you most want people to understand about what it means to live your whole life with sickle cell disease?

SPEAKER_0
[00:42:22,031]Um, I'm gonna say, um, they don't have to judge to judge you guys. Look at me, I'm sick and sad but you can't see.

SPEAKER_0
[00:42:34,791]Mourinho as well. You saw Mourinho, she's nice. She's when she said, "Oh, I'm sick of..." Hmm. It's like we are lying. Mmm. So they don't have to judge the person first.

SPEAKER_0
[00:42:50,891]like understand the situation of the person. So sometimes not easy to explain your private life, like your condition. But

SPEAKER_0
[00:43:05,931]if it's for, you know, something like that. Now they teach them, they know they're better.

SPEAKER_1
[00:43:14,681]Okay.

SPEAKER_0
[00:43:15,621]Now they're better because I remember when Marvin was little, when they had to carry Marvin, sometimes I was crying.

SPEAKER_1
[00:43:27,081]Australia

SPEAKER_0
[00:43:28,191]He was screaming and so when I was coming I was shouting them. I was, I told them, "Hey, go away, leave my door to me." Oh, we have to, I don't care. Now it's too much.

SPEAKER_0
[00:43:44,101]is too much Nothing's we gonna have. So go away. I was doing that. Bom, hoje eu vou usar o gel. She was a baby.

SPEAKER_0
[00:43:51,561]issues four five six So step by step, they teach them how to do things. comme

SPEAKER_0
[00:44:01,981]step by step and we need we need to compensate, we need to be ready for something they're going to do to us, whether we we are sick or not, on the pain or crisis or whatever.

SPEAKER_1
[00:44:15,101]Okay.

SPEAKER_1
[00:44:17,041]Thank you for that. So we're going to move on to a section where we talk to you a bit about how you were growing up with sickle cell. What was it like growing up with sickle cell in France and did you feel well supported?

SPEAKER_0
[00:44:32,541]No, in front of the shoe. It's not the same. I don't know why. Because the nothing was done yet or it's very tiny. In compared here. Here.

SPEAKER_0
[00:44:52,391]here It's why I'm still here.

SPEAKER_1
[00:44:56,251]Yeah.

SPEAKER_0
[00:44:57,271]I compare when I was there and when I'm here. You know, not about me, but me, I'm more than fifty today, so I just have to clap because I'm more than fifty and I'm still good. Even when I'm crisis, I know how to cope now and

SPEAKER_0
[00:45:21,431]My family as well, my kids as well, they know exactly when I'm just starting to be not feeling well. Okay, mommy stop, you go in your room, we're going to do everything. Maureen start. Maureen she's become my nurse here when I'm sick.

SPEAKER_0
[00:45:39,661]So, I'm not complaining. I just said, I'm grateful.

SPEAKER_1
[00:45:47,211]Okay

SPEAKER_0
[00:45:48,131]and for the person I met here as well. The community, a lot of community helped me. Um, so many things were stopped.

SPEAKER_0
[00:45:58,511]when I came here, it was 2010. Morgan was four. uh it was like a, there was like a nurse.

SPEAKER_0
[00:46:10,751]a nurse between hospital and uh sickle cell patient in the section

SPEAKER_0
[00:46:19,501]When Morina high, I was not feeling well. I was calling Barbara. Ah Barbara, I'm not feeling well. Morina as well. Okay, I'm coming to her room now. She's coming to check Morina, blah blah blah. Okay, now, now she need to go to the hospital. She was calling hospital emergency. That was wonderful. But this is was gone. It's not anymore. So I don't know why, but it was very, very helpful.

SPEAKER_0
[00:46:50,911]A sustained musical note plays.

SPEAKER_1
[00:46:52,051]So, this is going okay. So thinking about back home or back in France when you first got the diagnosis, how did the family handle it? Do you think they were prepared for news like that? Your parents?

SPEAKER_1
[00:47:10,151]Tell us a bit more about them.

SPEAKER_0
[00:47:12,921]balloon

SPEAKER_1
[00:47:17,821]No, don't worry. They didn't know what disease it was.

SPEAKER_0
[00:47:23,781]No, they didn't know because um in Africa it's like they don't explain, it just comes in pandemic like this. They say, uh, my mum, my dad, baboon.

SPEAKER_0
[00:47:36,621]And until now, a lot of parents they don't know.

SPEAKER_0
[00:47:40,881]I think now in in the they're trying maybe now to know more to go ask but before that they didn't know my parent they were surprised but they have to cope to accept.

SPEAKER_1
[00:47:58,391]Okay. So once you got the diagnosis, what was the healthcare like as a young person in Africa?

SPEAKER_0
[00:48:08,391]Non, pas exactement.

SPEAKER_1
[00:48:11,331]There wasn't nothing in place like that.

SPEAKER_0
[00:48:14,551]very much

SPEAKER_1

[00:48:15,741]Was there anything good at all about going to hospital?

SPEAKER_0
[00:48:20,171]Africa

SPEAKER_1
[00:48:21,861]in Africa and in France before he came to the UK.

SPEAKER_0
[00:48:26,591]Euh, non. Because in Africa, they don't know exactly. I don't know. And it's like um... I don't know what to say.

SPEAKER_0
[00:48:41,431]they don't even they know they don't want to say to the person. They're hiding the situation.

SPEAKER_0
[00:48:51,751]So, like me, if I manage, if I plan to go in Africa, I need to prepare myself because I know that some hospital can take care of me if I have the crisis.

SPEAKER_0
[00:49:08,691]So I have to manage my body before going. and bring a lot of things. Inkass

SPEAKER_1
[00:49:16,681]in case

SPEAKER_0
[00:49:17,501]and don't stay longer.

SPEAKER_1
[00:49:23,391]Okay. Right, so what tools or methods did you use to manage the condition when you were growing up in the absence of the care that was missing in Africa? How did you manage?

SPEAKER_0
[00:49:38,791]Ähm, äh, vorher kann ich nicht sprechen.

SPEAKER_1
[00:49:43,311]Only in Africa.

SPEAKER_0
[00:49:45,011]Aí na faculdade você vê.

SPEAKER_1
[00:49:46,851]baby

SPEAKER_0
[00:49:47,571]I was three years old. I think my father is not exactly He told us she's sick or something. That's it.

SPEAKER_1
[00:49:56,321]set

SPEAKER_1

[00:49:57,101]What age did you go to France?

SPEAKER_0
[00:49:58,851]Three years.

SPEAKER_1
[00:49:59,811]Oh my, so. Okay. So how were you managing in France?

SPEAKER_0
[00:50:07,541]My mum was, well, my mum was so afraid about my situation. But she was at the moment. My dad was there and that was giving the force to my mom. No, don't be afraid.

SPEAKER_0
[00:50:26,491]I'm here, mommy else, everything's gonna go okay, and now she's sick, leave her like this. So they did that all the time when I was too young until I'll be able to take care of myself and to learn myself.

SPEAKER_0
[00:50:48,051]Right.

SPEAKER_1
[00:50:49,421]So we talked about coming to the UK and how the doctor encouraged you. So that was what brought you to the UK? And how old were you when you arrived?

SPEAKER_0
[00:51:06,261]I think um more than fourteen, no yeah. I'm here since two thousand and ten.

SPEAKER_1
[00:51:15,861]Okay, and you came because there was a job opportunity.

SPEAKER_0
[00:51:19,931]Yeah, job opportunity and uh start a new life. I need something new because I've, uh, I've got three kids, I've got a divorce, it was like a something been broken.

SPEAKER_0
[00:51:34,811]Yeah, something was broken. Marine was hospital all the time, all the time. I don't know if maybe the family situation at that time makes me feel all the time in hospital. So I was so sad.

SPEAKER_0
[00:51:51,481]difficult, something was difficult at that time. And I don't know, this opportunity came. I don't remember, but something like this came on my way.

SPEAKER_0
[00:52:04,931]And it's like I was like this with my situation, sick, marine, reader, and something's came and my head during this. Show me another way.

SPEAKER_0
[00:52:19,031]So

SPEAKER_0
[00:52:21,801]I just said, okay, that's a new life for us. And I guess I have to ask the doctor first. Yeah. When I explained to the doctor, she told me go.

SPEAKER_1
[00:52:34,831]It was like a timely intervention.

SPEAKER_0
[00:52:37,671]And I was so wrong.

SPEAKER_1
[00:52:39,891]Yeah

SPEAKER_0
[00:52:40,261]Das ist ein bisschen viel. Donc, qu'est-ce que ça va se passer ?

SPEAKER_1
[00:52:43,351]Right. Right. So if you think of when you arrived, how was it like registering with the NHS for the first time as someone living with sickle cell? Do you think they understood the condition at the time?

SPEAKER_1
[00:52:59,581]So what's the registration smooth?

SPEAKER_0
[00:53:02,741]The things we can do is French.

SPEAKER_1
[00:53:05,041]Okay.

SPEAKER_0
[00:53:05,621]English was difficult to wait wait to speak.

SPEAKER_0
[00:53:09,221]So they was very calm. They they find someone speak French to translate to make me comfortable or even my kids moving as well. So the thing was done step by step. There was a prayer that was okay, take your time, everything's going to be slowly. So I will just stay, Marie, one night. Step by step, the appointment first appointment came with someone speak French. Was very helpful.

SPEAKER_1
[00:53:42,661]Okay. Okay. That's good to know.

SPEAKER_1
[00:53:48,801]Here. So how did the NHS here in the UK compare to the experience you had outside of the UK? What surprised you? What were you not expecting?

SPEAKER_0
[00:54:00,581]Mmm, welcoming.

SPEAKER_0
[00:54:04,321]Yeah. I wasn't expecting that. the initiative and initiative is personal to send It's so...

SPEAKER_0
[00:54:13,351]I don't know for another person, but for me, in French it's like you're just a number.

SPEAKER_1
[00:54:20,111]uh

SPEAKER_0
[00:54:21,401]No, just a number. And here, there's also someone, a person, uh, a situation.

SPEAKER_1
[00:54:31,721]They see you.

SPEAKER_0
[00:54:33,561]Yes

SPEAKER_1
[00:54:34,241]Let's see. Okay. So was there any moment where you felt like being from abroad has affected how you were treated by the healthcare professionals?

SPEAKER_0
[00:54:48,661]No It was better before now because they stopped a lot of things.

SPEAKER_0
[00:54:57,461]It was beat back before now it was better.

SPEAKER_1
[00:55:03,041]Before now, things were better. What has changed?

SPEAKER_0
[00:55:06,331]because um the thing was like a little nurse who's helping some person.

SPEAKER_1
[00:55:15,141]Yeah.

SPEAKER_0
[00:55:15,751]their condition

SPEAKER_0
[00:55:16,821]So the the things, I don't have to go to the hospital straight away. Have someone can listen to me properly and see if I need this support or this one or this one. So now the staff is not anymore, this services, you know. It was from NHS.

SPEAKER_1
[00:55:37,851]Yeah. So some services have stopped. Yes.

SPEAKER_1
[00:55:42,171]Yeah. That's why we are moving on to about your personal experience with the NHS care, 'cause we want to know like overall, has the NHS looked after you over the years? What has worked well and what has let you down?

SPEAKER_0
[00:55:57,641]Yeah, there's no looking anymore.

SPEAKER_1
[00:55:59,581]Hmm

SPEAKER_0
[00:56:00,651]one year can if I'm not very sick, going to the hospital they don't, it's like they don't know me anymore.

SPEAKER_0
[00:56:09,471]before that, there was someone was oh, how are you? I'm getting

SPEAKER_0
[00:56:15,061]okay, I'm coming every like two, three months. Someone was coming check, see how you feel, how we can help you, your condition, your home, how easy. So, I remember other time I was living in... was Forzi Road.

SPEAKER_0
[00:56:33,591]at home, no washing machine, nothing and every Saturday I was carrying all the kids, Morine, Solene, my son, going to the washing machine outside because I I have to wash everything for the weekend before Monday, before school started.

SPEAKER_0
[00:56:53,031]When when I explained to her my situation, how we can help you and what team I set up. Are you sure? Oh yeah, we are here to help.

SPEAKER_0
[00:57:01,541]So when I explain the situation, uh, one week after, they bring a washing machine for me.

SPEAKER_1
[00:57:08,571]That's good.

SPEAKER_0
[00:57:09,991]You see, and all that service will stop.

SPEAKER_1
[00:57:14,011]So that lets you down.

SPEAKER_0
[00:57:16,181]Yes. It's uh, I don't know why. But they helped me at the time and uh account

SPEAKER_1
[00:57:24,721]Can't get into a system anymore. Yeah, so have you

SPEAKER_1
[00:57:30,221]Have there been times when you felt dismissed or not taken seriously at the hospital when you were in crisis or needed to go to the hospital for sickle cell? Can you tell us a bit about what happened?

SPEAKER_0
[00:57:46,811]the things um for me, I learned how to manage myself. So I wasn't going to the hospital all the time. I prefer to stay home.

SPEAKER_0
[00:57:58,101]When you go into the hospital in emergency, sometimes you stay 24 hours. This chair is comfortable. Sometimes it's like this. And when you're in pain, it's not.

SPEAKER_0
[00:58:14,171]So, I manage my pain, my crises. If... if I can manage at home, it's better for me to stay home, take medication, and check the temperature, something like that.

SPEAKER_1
[00:58:31,701]Да.

SPEAKER_1
[00:58:34,381]Okay.

SPEAKER_1
[00:58:35,671]The next question sounds like you've already answered, but I'll ask anyway. How has your care changed over the years since you have been in the UK? Is it better now than when you first arrived?

SPEAKER_0
[00:58:49,651]Nah

SPEAKER_1
[00:58:50,341]It's worse.

SPEAKER_0
[00:58:51,111]sí

SPEAKER_1
[00:58:53,051]and that's because most of the services have stopped.

SPEAKER_0
[00:58:57,331]astounding

SPEAKER_1
[00:59:00,691]What what would you like?

SPEAKER_0
[00:59:03,351]the things that service was very helpful.

SPEAKER_0
[00:59:12,011]there's so many person in the emergency. They complain because some some of them they don't have to go there.

SPEAKER_1
[00:59:21,111]Yeah.

SPEAKER_0
[00:59:22,101]or they have to see like a GP or someone else.

SPEAKER_0
[00:59:26,441]the nurse was coming here, she was coordinate, she was source, she knew the situation and she was, okay, now Maureen, you can stay home. But take your medication, we're going to see two or three days, how you feel.

SPEAKER_0

[00:59:41,491]and it was good. And even for me, I was lucky. My stress was down because someone came, someone from NHS, someone from hospital to check my daughter.

SPEAKER_1
[00:59:54,991]So there was no need for you to go into hospital.

SPEAKER_0
[00:59:58,071]to confirm to me, okay? Now man, don't stress. Maurice is going to be okay. She's just having stress. That's the... It's too sad. Some service like that will stop.

SPEAKER_1
[01:00:13,601]Was war das? Hauptsache, du hast es gehört. Okay Thank you for that.

SPEAKER_1
[01:00:18,331]We're going to move on to how you raised your daughter also with sickle cell. When you found out about your daughter had sickle cell disease, how did that feel knowing that you already knew what it was like living with it?

SPEAKER_0
[01:00:36,121]you know, I wasn't afraid because I know the things. So, I just when Maurie's she's on a crisis, when she was young, now it's better because now she knows how to cope, how to... I I was telling Maurie, okay, step by step, you're going to recognize a crisis, your body, your body tells you something. So sometimes we don't... So step by step, I I like teach Maurie how to do just like I did for myself.

SPEAKER_0
[01:01:13,951]Sometimes he was okay, sometimes not. But I was doing it again and again until it's perfect.

SPEAKER_1
[01:01:21,531]Yeah. Okay So has raising a daughter with sickle cell changed how you think about your own experience with sickle cell?

SPEAKER_0
[01:01:32,631]Yes

SPEAKER_1
[01:01:33,811]Okay

SPEAKER_0
[01:01:35,431]because my experience, it's my understanding, my comprehension, my feeling, and Marina and I, we are totally different.

SPEAKER_1
[01:01:47,841]Yeah.

SPEAKER_0
[01:01:48,711]So I have to cope as well with her feeling.

SPEAKER_0
[01:01:53,571]So I learned.

SPEAKER_0

[01:01:56,031]so sometime I don't have to pressure too much because she's moving with her stresses like more than me. So I have to to learn because I was all the time when moving would like to do something like a sibling. I mean, they're gonna come with, they're gonna run, they're gonna jump, they're gonna jump. Move. Are you sure?

SPEAKER_0
[01:02:23,921]Oh yeah, no problem. So sometime maybe it was wrong. I should let Marine go with them.

SPEAKER_0
[01:02:33,461]But I was afraid as well, no, Maureen, you're gonna come back and you're gonna not feeling well. And I realized as well, um, for the sibling, there was hold on, Maureen, don't do that.

SPEAKER_0
[01:02:48,381]Don't do this. It's going to be safe. Morgan, stop! Na, aber wie geht's? Mhm, that's not good.

SPEAKER_1
[01:02:56,361]Just let her be and enjoy her life, yeah?

SPEAKER_0
[01:02:59,861]souls and after that, I look at it and I'm going to change how to

SPEAKER_0
[01:03:05,701]And I told her, "Don't tell Maurice, don't do this, don't do that." She can do everything she wants to do. She's just gonna do... she's gonna find a way to do that. Yeah.

SPEAKER_1
[01:03:18,531]Okay. right So, did you notice any difference in the way your daughter was supported compared to how you were supported back then?

SPEAKER_0
[01:03:31,741]by the hospital bathroom

SPEAKER_1
[01:03:34,451]by the NHS

SPEAKER_0
[01:03:35,541]Mein Handy ist aus. Nothing to say.

SPEAKER_1
[01:03:39,061]You both receive the same level of support.

SPEAKER_0
[01:03:41,501]Yeah, December. Je ne sais pas mais bon. It was really kind of you. No problem.

SPEAKER_1
[01:03:48,901]Okay. So, what sort of advice have you given to her, your daughter, about managing her condition that came from your own experience?

SPEAKER_0
[01:03:59,281]Sinto to hear her body first Even moving like it. Mam, pomóż mi. Oh, careful.

SPEAKER_0
[01:04:10,841]If you hit too much here, you need to think your body, how your body going to respond.

SPEAKER_0
[01:04:20,101]So, oh yeah, maybe I'll put it again. Now I just eat too much, like my body start to, I'm not feeling well, okay, so you see. So you need, the things we need to help your body. Yeah.

SPEAKER_0
[01:04:33,431]The first thing, because the body gives a sign for something's coming.

SPEAKER_0
[01:04:39,731]So she started to meet you. Now, it's better. Chinona

SPEAKER_1
[01:04:46,031]Okay.

SPEAKER_1
[01:04:48,891]Thank you for that.

SPEAKER_1
[01:04:50,681]Alright, so we moved along just a few more and we'll be done. So looking back and looking forward, what has living with sickle cell across two countries and two generations taught you?

SPEAKER_1
[01:05:05,351]'Cause you've got the disease since you were a child, you moved from Africa to France, and then from France you had your own family, and then you've come down to the UK. What is the lesson that what have you...

SPEAKER_0
[01:05:19,781]it's something on you

SPEAKER_1
[01:05:21,291]B♭

SPEAKER_0
[01:05:21,921]Even if you go anywhere, it's on you. So you have to live with the situation. So it's better for you to know your body, to know your condition. No one's gonna know better than you.

SPEAKER_0
[01:05:36,611]that's the first concern and taking medication is very important. It's not gonna stop your situation, but it's help it's gonna help you now.

SPEAKER_1
[01:05:49,061]Mhm In the future.

SPEAKER_0
[01:05:50,781]perfect

SPEAKER_1
[01:05:51,431]Yeah

SPEAKER_1
[01:05:53,681]Okay.

SPEAKER_1
[01:05:55,011]So what do you wish had been different about the care you received? You won't remember Africa much, but knowing Africa as it is and then France and the UK, what do you wish was different about the care had been different, especially in France when you were aware?

SPEAKER_0
[01:06:17,451]Yeah, but it's just uh no one helping you. No one.

SPEAKER_1
[01:06:22,871]You wish they understood the disease more.

SPEAKER_0
[01:06:26,021]Like here. Yeah. No one helping you.

SPEAKER_0
[01:06:33,701]And that that's gonna be unfair.

SPEAKER_1
[01:06:41,761]Right.

SPEAKER_1
[01:06:43,321]So looking forward into the future, what gives you hope when you think about the future of sickle cell care for your daughter and for yourself? What what what is the hope there?

SPEAKER_0
[01:06:56,581]My hope is just to, so Maureen is gonna be good. That's definitely, she's just gonna find her way and she's gonna cope with problems.

SPEAKER_0
[01:07:12,951]Yeah, she's gonna find everything's gonna be. We are in a good place.

SPEAKER_1
[01:07:19,711]Okay.

SPEAKER_1
[01:07:24,211]Okay, um, in this last question we're hoping that you will mention that you hope there are more charities like Plasma that can help. Okay, so I'll just ask that question again.

SPEAKER_1
[01:07:38,331]So, what what gives you hope when you think of the future of sickle cell care for your daughter and its generation?

SPEAKER_0
[01:07:50,871]but they need a help for their for their their work experience. They spend a lot of time in the hospital. And now they're coming adult. And they don't know which way they're going to go. They have to manage our sickle cells. So they need like a community service will help all the young sickle cell patients give them the opportunity to go do a training here, do something here to have them by self themselves experience for their future.

SPEAKER_0
[01:08:30,601]that's the consider that. Because Maureen, she's twenty, she's struggling, she don't know, she... ma'am, where am I gonna go? What do you think I'm gonna do?

SPEAKER_0
[01:08:42,341]but that a lot of young black Marines they need help like this.

SPEAKER_0
[01:08:48,901]They don't have to leave them because when there was like a fourteen sixteen there was with someone with a group to help them, but now they're becoming adults. So they just leave them.

SPEAKER_0
[01:09:02,861]Okay, now you have coming a duty, you need to find a way which course you want to do or which... They don't have a friend as well?

SPEAKER_0
[01:09:11,231]So starting something small like group to show them they're gonna have like a community they're they're gonna learn to have friends to socialize because Marvin she's all the time at home.

SPEAKER_1
[01:09:26,361]Yeah, they need to fit into society.

SPEAKER_0
[01:09:28,811]all the time Pour ce qui est de mon livre, c'est comme ça. even she's outside, she's gone to the cozy club. herself But she's comfortable in this position.

SPEAKER_0
[01:09:41,581]But when it's not good, someone even go with your sister to the party. morning, can we pass on now?

SPEAKER_0
[01:09:51,321]That's me, man, make me so sad. so I might have some fun.

SPEAKER_0
[01:09:58,611]I know how to go here to speak with someone. So, for her and I think a lot of young like Maureen because they just was hospital. Oh, it's difficult.

SPEAKER_1
[01:10:14,441]Okay. Thank you.

SPEAKER_1
[01:10:17,731]Thank you so much, Albita. That's the end of the interview. Your story and your daughter's story are going to mean a great deal for when we put this together for anybody who hears the interview. Thank you so much for your time. Okay

SPEAKER_0
[01:10:33,381]Thank you.