Nicole - Audio.m4a

Heritage Stories: Sickle Cell Disease Oral History Interview

Summary Of Speaker Contributions

Facilitators (Speakers 0, 2, 3, and 4): Managed the technical setup and conducted the oral history interview. They focused on creating a supportive environment for the interviewee, emphasizing the importance of documenting personal experiences to advocate for better healthcare and community support.

Nicole Warner (Interviewee): Shared her personal journey living with sickle cell disease, detailing her diagnosis, pain management strategies, and the emotional impact of the condition. She contributed insights regarding the lack of local support services in Walsall and the positive impact of connecting with the "Plasma of Hope" charity.

Key Points And Decisions

Project Objective: The team agreed that the primary goal of this session is to capture oral histories to raise awareness about the evolution of sickle cell treatment and the current gaps in support services.

Healthcare Challenges: Nicole noted that healthcare professionals often lack sufficient knowledge regarding the severity of sickle cell pain, leading to instances where patients feel overlooked or dismissed in clinical settings.

Community and Isolation: There was a consensus that individuals living with sickle cell often face significant isolation. Nicole highlighted that community support is currently inadequate, and peer connection is vital for mental well-being.

Empowerment: The participants agreed that sharing these stories is an empowering act that helps reduce stigma and provides hope to others who feel they are navigating the condition alone.

Next Steps And Commitments

Facilitators: Committed to editing the interview footage to highlight the necessity for improved community and hospital-based support services. They also plan to continue the project by interviewing other individuals, such as Shona, to broaden the scope of the heritage collection.

Nicole: Committed to participating in the project and sharing her story, despite initial nervousness, to help others feel less isolated and to advocate for better awareness of the condition.

SPEAKER_0
[00:00:00,472]Okay, speak now.

SPEAKER_1

[00:00:01,852]Testing testing one two three. Testing testing one two three.

SPEAKER_0
[00:00:05,422]Okay, that's better.

SPEAKER_2
[00:00:07,302]Yeah.

SPEAKER_2
[00:00:09,782]And then I created all this telephone and yeah, that's fine. Um, can you put the mobile?

SPEAKER_0
[00:00:17,792]Tchau

SPEAKER_2
[00:00:18,702]Plasma mobile yeah okay.

SPEAKER_0
[00:00:20,942]Yeah, he was breaking up. Okay.

SPEAKER_2
[00:00:23,332]spoil it then just just don't have to do anything else

SPEAKER_0
[00:00:27,002]Right.

SPEAKER_2
[00:00:28,582]And then for that section you call plasma or four. Okay.

SPEAKER_0
[00:00:48,232]So.

SPEAKER_2
[00:00:49,202]and turnover. So we have improvisical activity, additional instruction. Yes. extra extra services Yeah. Improve

SPEAKER_2
[00:01:02,372]or see peer connection. Finance and debt management. uh no. yeah, finance and debt management, yeah. yeah, yeah. oh.

SPEAKER_2
[00:01:12,402]Uh... Maybe it's a structure of information.

SPEAKER_0
[00:01:16,822]Could you speak to Nicole for a second?

SPEAKER_2
[00:01:18,702]Yeah, Tuffy, good morning, Tuffy. Hello, hello. Thank you. How are you? I'm fine, how are you? Good, thank you.

SPEAKER_0
[00:01:26,292]Hey, that's good.

SPEAKER_2
[00:01:27,392]哎呀，那个。呃。

SPEAKER_2
[00:01:33,422]We are taking huge development such as first aid cooking.嗯，我给你读吧。我们先去吃点东西。你这是到处都有酒水。

SPEAKER_2
[00:01:46,382]说 Yeah, that's funny nutrition. Yes. True.

SPEAKER_2
[00:01:56,952]It's true, but it's not like that. I hope you guys know what I mean.

SPEAKER_0
[00:02:01,502]走吧。

SPEAKER_2
[00:02:02,792]嗯。你懂我的意思吗？

SPEAKER_0
[00:02:06,342]Are you gonna warm up again?

SPEAKER_2
[00:02:07,922]Maybe contact his name on the packet and jump back to this one. Yeah, that one's right.

SPEAKER_2
[00:02:16,232]And who are they? Are they? Are they asked? Who are they?

SPEAKER_2
[00:02:28,582]Do you want me to change your telephone number yet? Just put the mobile. So, um, let me see if I can get this.

SPEAKER_2
[00:02:38,892]Alright, so this is where you're going to put...

SPEAKER_2
[00:02:47,292]And the email, is the email okay?

SPEAKER_0
[00:02:49,592]I think I'm good to go.

SPEAKER_2
[00:02:50,732]Yeah, email, okay, email. Is it info? Yeah. Uh, no, put Mary C, put my email. Okay. It's really weird.

SPEAKER_0
[00:03:00,772]I believe so.

SPEAKER_2

[00:03:02,282]All right. If you haven't sent it yesterday, ask him, I know it's another, send it to your phone, yeah? Alright, well, um, we've been talking, we have until 4 o'clock to send it, so let's pack it and get on with this.

SPEAKER_2
[00:03:16,322]I'll leave you my phone. Um, if you need to. Yeah.

SPEAKER_2
[00:03:30,082]Oh, sit down, Jim. He looks so nice. Thank you. Right.

SPEAKER_0
[00:03:41,022]Um, I have to be careful about using that screen and keyboard.

SPEAKER_2
[00:03:46,442]Really?

SPEAKER_0
[00:03:47,312]Yeah. Shouldn't work. I mean, yeah. Are you okay with that?

SPEAKER_2
[00:03:51,222]Yeah, I could still see it. Cool. Okay.

SPEAKER_0
[00:03:55,432]Um, I'm just gonna do the test shot.

SPEAKER_2
[00:03:57,302]Mm-hmm.

SPEAKER_0
[00:03:58,132]Look at that.

SPEAKER_2
[00:04:00,642]Don't worry, I'll do this. Oh, it came in handy.

SPEAKER_2
[00:04:08,662]Did you come with a pen? You know? I think so. No.

SPEAKER_0
[00:04:21,192]Okay, I think that's probably all.

SPEAKER_2
[00:04:23,462]I'm sure you're positioned okay.

SPEAKER_0
[00:04:25,732]Yeah, yeah. Let's work.

SPEAKER_2
[00:04:27,792]Okay.

SPEAKER_0
[00:04:28,462]There's a couple of shadows that are hard to get rid of, but I'll give you another light for that.

SPEAKER_2
[00:04:32,382]John's always at the door. There's no door.

SPEAKER_0
[00:04:34,732]No, it's alright. It's alright. These two lights.

SPEAKER_2
[00:04:38,012]What am I doing?

SPEAKER_0
[00:04:39,072]lights are creating the shadows, that's all.

SPEAKER_2
[00:04:40,672]Oh, it's great.

SPEAKER_0
[00:04:41,772]So from a... from a miniature... that's what we've done. So you just ground the chairs. Oh, yeah.

SPEAKER_2
[00:04:48,882]Oh my god, that looks nice.

SPEAKER_0
[00:04:49,972]It does, doesn't it? Wow. So we can move into the grid.

SPEAKER_2
[00:04:52,892]Yeah, yeah, we can. Sorry. Ready? John, put your door handle in front of you. That's really nice. All right. Thanks, yeah. Okay. We should do your testing and then...

SPEAKER_2
[00:05:07,182]Ooh. And after all you've been following me. Uh, so good morning. Hi Nicole, it's lovely to meet you again.

SPEAKER_2
[00:05:17,212]So, um we're here, you know, as part of the heritage stories project which we discussed a couple of times.

SPEAKER_2
[00:05:27,202]And the whole aim of this pro- uh project is to um speak to you about your experiences uh living with sickle cell disease and just to see how

SPEAKER_2
[00:05:38,872]um sickle cell management and treatment has evolved throughout the years. So

SPEAKER_0
[00:05:45,542]Sorry.

SPEAKER_2
[00:05:46,172]Я на лавочке сижу.

SPEAKER_0
[00:05:47,652]Huh? Are you watching it or what?

SPEAKER_2
[00:05:48,912]Yeah, watch your machine. Can you hear it in the background? Oh, can we pause it? No? Yeah.

SPEAKER_0
[00:05:54,782]Ah

SPEAKER_2
[00:05:55,112]understand I'll have a look. Please. I'll tell you. Yeah.

SPEAKER_0
[00:06:00,062]It's up to you really. I mean, I don't, I mean we couldn't, we can go with it and let it roll and it's a natural thing.

SPEAKER_2
[00:06:05,622]If it can be paused, pause it. Pause it. Okay. 'cause it's just gonna pick up in the background. Yeah, yeah, yeah.

SPEAKER_0
[00:06:12,522]I think it's all sensitive. I think it's all

SPEAKER_2
[00:06:14,972]That's a good mic. Hmm. Um. Yeah.

SPEAKER_0
[00:06:18,612]Again, I'm saying if you wanted to go with it, like it's a natural thing, like

SPEAKER_2
[00:06:21,862]I know, right? Yeah.

SPEAKER_0
[00:06:23,652]Okay. Alright.

SPEAKER_2
[00:06:25,002]Right, let's start again.

SPEAKER_0
[00:06:26,132]one second sorry

SPEAKER_2
[00:06:27,012]Okay, no worries.

SPEAKER_2
[00:06:30,362]Gonna have a very quick look to see

SPEAKER_2
[00:06:43,292]This is like seventeen five inches or something. I think so. Mhm. Massive.

SPEAKER_0
[00:06:51,352]This is how it looks when you look or this is because I've been a text star.

SPEAKER_2
[00:06:57,272]Oh yes. Ah! Yes. Yeah. Yeah. Very nice. Looks like I've got made up looks.

SPEAKER_0
[00:07:05,772]Thank you for listening.

SPEAKER_2
[00:07:06,932]Yes. Okay.

SPEAKER_0
[00:07:10,202]One second, y'all.

SPEAKER_2
[00:07:19,902]Oh, do you think I need a mic? No. Mmm.

SPEAKER_0
[00:07:24,562]I bought one.

SPEAKER_2
[00:07:28,382]I think we are right.

SPEAKER_0
[00:07:30,032]it's up to you really. I have bought one if you want to do my talk.

SPEAKER_2
[00:07:34,902]Good night. As long as you can get it, I don't mind whichever.

SPEAKER_0
[00:07:38,552]I'll hear your voice but obviously it's going to be fainter than

SPEAKER_2
[00:07:40,892]Yes. Nicole? No, we need hers to be more...

SPEAKER_0
[00:07:43,692]C

SPEAKER_2
[00:07:44,152]Yeah. Yeah. Because it's all about their voices, not mine.

SPEAKER_0
[00:07:49,942]Yeah. In this particular

SPEAKER_2
[00:07:51,752]Yes

SPEAKER_0
[00:07:52,502]All right, okay. Yeah. Okay then.

SPEAKER_2
[00:07:54,312]Alright. Good.

SPEAKER_0
[00:07:55,252]All right, cool. So, I'm gonna say roll in a second now.

SPEAKER_2

[00:07:58,912]Okay.

SPEAKER_0
[00:07:59,832]We've got about sixty-seven minutes of power on this battery then. We might have to pause while I put a new battery on.

SPEAKER_2
[00:08:06,342]I think you said too much. Did you know?嗯嗯 Ну что, поехали.

SPEAKER_2
[00:08:15,072]你很认真听我说话。 You did.

SPEAKER_0
[00:08:21,312]Okay, we're good to go.

SPEAKER_2
[00:08:22,722]Okay. Hi Nicole, good morning. Thank you for having us here. So today we're going to... Sorry, sorry, it's alright. Yeah, sorry, it's alright.

SPEAKER_0
[00:08:31,522]Terrible issue.

SPEAKER_2
[00:08:32,512]Ja, maar They haven't, they haven't really talked to you here, no. Mm-hmm. Okay, then. Cause everyone else will receive theirs. Haven't heard anything. Okay.

SPEAKER_0
[00:08:46,082]Okay, this time, good to go.

SPEAKER_2
[00:08:49,892]Okay. All right. Hello again. Hey Nicole, good morning.

SPEAKER_2
[00:08:57,492]Thank you for having us here at your lovely home. So today we are here as part of the heritage um uh heritage project capturing stories of individuals with sickle cell. So this is

SPEAKER_2
[00:09:12,192]heritage oral history, um sickle cell stories then and now. So, this is just an informal discussion just to understand how sickle cell has impacted your life.

SPEAKER_2
[00:09:24,322]and the whole idea is for us to understand how sickle cells have evolved, if at all. So we're going to be asking you some

SPEAKER_2
[00:09:32,352]questions about how it affects you, how you live your life with it, you know, and the treatment and everything, you know, sickle cell. So I'm going to start with some personal experience questions and diagnosis.

SPEAKER_2
[00:09:44,992]So when were you diagnosed with sickle cell and how was it explained to you? Um, I was diagnosed with sickle cell at birth. Um, how it was explained to me, um, oh my gosh, sorry,

I'm so nervous.

SPEAKER_2
[00:09:59,402]It's okay, it's okay, it's okay. Take your time, take your time. Huh? It's absolutely fine. Do you, I mean, wait, wait, wait. So, where were you born? in Birmingham. Um yeah, I was born in Warsaw. awesome

SPEAKER_2
[00:10:13,392]Yeah. Okay. Okay. And obviously there is this newborn sickle cell screening so that screen, you know, every child that is born, which is good, you know, not many people get diagnosed when they're born.

SPEAKER_2
[00:10:26,672]So, how did you feel? I mean, as a baby you probably wouldn't have understood much. At what point did you understand that you had sickle cell? Um, and did you, you know...

SPEAKER_2
[00:10:40,992]Once I was in primary school, I noticed that I had a lot of episodes. I had a lot of pain. Um, I noticed that I couldn't um be as active as the other children. I wouldn't be able to keep up.

SPEAKER_2
[00:10:54,572]um like running and playing in the snow as well. Like I used to like playing in the snow when I was a little girl. Um, my mum used to tell me not to go outside and play in the snow because it would affect me and I would end up in pain. Um

SPEAKER_2
[00:11:12,032]Ugh. No, that's good, that's good. I mean, how old are you? We should have started by asking that. How old are you? I'm twenty-seven. Okay, so obviously, um, you like to play in the snow and, you know, your mom would tell you

SPEAKER_2
[00:11:26,052]you know, it'll affect you. Did she explain to you about sickle cell?

SPEAKER_2
[00:11:30,752]Um, no, not until I got older, until I was like, um, in secondary school, like year seven, I fully understood what sickle cell was. I wasn't really um explained like how I inherited the um disease.

SPEAKER_2
[00:11:48,232]I mean, how did it feel? Were you very sick when you were younger? Um, yeah, I would be in bed most of the time, um handling the pain. Um... um...

SPEAKER_2
[00:12:02,832]Did you go to hospital? No, I actually dealt with my episodes at home. I didn't start going to the hospital for treatment until I was um in my twenties.

SPEAKER_2
[00:12:13,282]Oh, really? That's good. Yeah. Right. So what sort of things were you using to manage the pain at home?

SPEAKER_2
[00:12:18,352]Oh, so I was given over-the-counter painkillers, such as paracetamol, ibuprofen.

Um, my mum used to give me massages in the areas where I had the pain. Um, I tried to drink as much water to stay hydrated, 'cause I know that helps with the um eases the pain as well.

SPEAKER_2
[00:12:35,992]Yeah, yeah. That's really good. And I know sickle cell affects people differently. Are you able to describe what a typical crisis feels like for you?

SPEAKER_2
[00:12:47,292]And you know, how do you manage, obviously explain how you manage it, but how does a typical crisis affect you?

SPEAKER_2
[00:12:56,142]Okay, so if I have a crisis in my arm, um it usually starts in like my joints and then it slowly starts to spread. Um it doesn't just affect my arm, it affects my whole body, like my neck, my shoulders, and sometimes like one side of my back, um gets affected. Um, I feel really drowsy.

SPEAKER_2
[00:13:17,052]Um, I'm in the... I'm bedridden as well. Um, I can't really do things for myself. I have to ask... I ask... I have to ask my family members. That's my dad. Sorry guys. It's okay, it's fine.

SPEAKER_2
[00:13:31,942]Um, I have to ask my family members to help me, um, to get dressed and eat. Rumble Okay. Oh, you can just come here, you can edit it. Yeah.

SPEAKER_0
[00:13:42,752]Well, I mean, of course, just tips, so... Just to say hi. Yeah.

SPEAKER_2
[00:13:51,382]Hello. Thank you. Hello.

SPEAKER_2
[00:13:56,412]Sorry, we're intruding. Nice. Yeah, good, good, good. We're just going to carry on. You're doing really well. Thank you. I feel so nervous. Yeah. That's okay. Yeah, carry on.

SPEAKER_2
[00:14:08,712]So, um, my next question is, how did you feel emotionally? I know this is something that we don't talk a lot about, especially for people that live with sickle cell. Yeah. I mean, how did you feel emotionally when you first became aware of living with sickle cell?

SPEAKER_2
[00:14:26,172]Um quite isolated because I don't have any other family members that have the full trait of sickle cell just like the traits.

SPEAKER_2
[00:14:33,882]Um, I remember my dad. He told me that when he was younger, he used to suffer with sickle cell but not on the same level as how I dealt with it. Um, he said that he used to have a stiff neck, but he didn't know what caused it until um...

SPEAKER_2
[00:14:51,382]Was that noise? Does he have sickle cell? He has a trait. He has a trait. Yes, okay. What was the question again?

SPEAKER_2

[00:15:00,712]No, mental health. Oh yeah. Um.

SPEAKER_1
[00:15:03,782]consolidated

SPEAKER_2
[00:15:04,712]isolated Did your friends understand sickle cell? Um, not really, no. They didn't really have an understanding of sickle cell. Is that why you felt quite isolated? Yeah

SPEAKER_2
[00:15:18,352]Yeah. Um, I'm going to be even talking about your current treatment and management. Yeah. So, what treatments or medications are you currently using to manage your condition?

SPEAKER_2
[00:15:34,782]I don't know how to pronounce it. Yeah. You know, the penicillin. Yes. I take that and um I take folic acid as well and um just multivitamins. Okay. Okay.

SPEAKER_2
[00:15:46,322]That's good. Um, have you been taking this since when you were diagnosed, since when you were a child? I haven't been consistent with it. Right. Should I keep it, should I be honest or, Oh yes, we... Okay. ...want you to be honest. I mean, it's okay.

SPEAKER_2
[00:15:59,722]Um, is it that you forgot to take it? Yeah. As long as you're keeping well, and when you remember you take it, that's what's important. Yeah. Yeah. So, um, and how do you manage pain on a daily basis?

SPEAKER_2
[00:16:14,112]Um, if I'm feeling a lot of pain, um

SPEAKER_2
[00:16:22,352]Hmm.

SPEAKER_2
[00:16:24,922]It's okay. Go remember, it's fine.

SPEAKER_2
[00:16:28,942]So if I'm feeling pain, I usually if I know that I have work the next day or something, I'll just um call in sick, take the day off so I can rest in bed, um take my painkillers.

SPEAKER_2
[00:16:42,602]um stay hydrated and um try not to do too much. It's getting much worse. How do you manage with work? Um.

SPEAKER_2
[00:16:56,462]Do your employers know that you've got sickle cell? Oh yeah. They know that I have sickle cell but since I've started working there, I haven't had any episodes just yet. So everything's fine. I'm sure there are things in place to support you.

SPEAKER_2
[00:17:10,162]Yeah should you not um feel well. Yeah. I do have the option to work from home. Are you under the care of any specialist sickle cell team? Um, yes, at the hospital, Birmingham

Hospital.

SPEAKER_2
[00:17:24,302]Okay, thanks, Katya. And what does the support look like? Have you always been on the, obviously you are 27, you used to be on the, when you were a child? Mhm. Under the pediatric team? Yeah.

SPEAKER_2
[00:17:39,722]How would you compare transitioning into adult care?

SPEAKER_2
[00:17:45,262]Um, the appointments are less frequent than how they used to be when I used to go to the Birmingham Children Hospital. Um, my appointments now are like every six months. From what I remember, um when I used to go to the children's hospital, it was more frequent, more regular.

SPEAKER_2
[00:18:03,912]Ähm ja. Yeah. Um, so how do you feel about the team currently? Do you think they give you enough support?

SPEAKER_2
[00:18:14,762]When it comes to your health, managing your condition. Yeah. Okay. Yeah. That's good.

SPEAKER_2
[00:18:22,962]And um do you feel that healthcare professionals have enough knowledge about sickle cells?

SPEAKER_2
[00:18:33,432]so for when you are not well, not necessarily your specialist team, uh, because they are specialized and they have a better understanding of sickle cell. Say when you're not feeling well, for instance, and you have to go to A&E if at all.

SPEAKER_2
[00:18:45,352]Hmm or have to go to hospital for any other reason. Do you feel that healthcare professionals have a good knowledge of sickle cell? Hmm.

SPEAKER_2
[00:18:53,982]I feel like not many health care professionals understand how severe the pain can be when it comes to sickle cell. Um, sometimes they can overlook or not take you seriously when you're feeling intense pain.

SPEAKER_2
[00:19:10,382]Okay. We're going to take a little break. Okay. Yeah, cool.

SPEAKER_0
[00:19:15,272]Can I work with you?

SPEAKER_2
[00:19:16,342]Леша С Right. Sorry.

SPEAKER_2
[00:19:35,602]Yeah. I just feel really nervous. Yeah.

SPEAKER_2
[00:20:16,502]Hi, good. Yeah. Yes. Yes. Yes. Yes. I just have to do the consulting. Right, so

SPEAKER_0
[00:20:27,162]director

SPEAKER_2
[00:20:28,512]Yeah, yeah, I'm a songwriter. Um, so you're doing really well so far. Thank you. Um, so I was just asking you about healthcare professionals. Um, their knowledge. Oh, sorry. We're good.

SPEAKER_2
[00:20:42,942]Have you, uh, can you think of any instances where you've had really good or bad, um, care?

SPEAKER_2
[00:20:51,042]Just can you explain if you've experienced a healthcare professional who did not understand your situation when you went into a hospital?

SPEAKER_2
[00:21:03,402]Um, so when I was in the hospital, I was feeling a lot of pain and um they were taking their time giving me the painkillers. Um, that's the only thing that I could think of at the moment.

SPEAKER_2
[00:21:17,162]Okay. No sense of urgency. Any idea how long you had to wait? Remember?

SPEAKER_2
[00:21:25,382]Um, around an hour. Okay. I believe. Okay.

SPEAKER_2
[00:21:33,192]So, um, in terms of community support, I know you mentioned that you're under the care of, uh,

SPEAKER_2
[00:21:41,772]the hospital in Birmingham. Um, have you been able to access any community support and growing up? Um.

SPEAKER_2
[00:21:53,152]Did you access, did your family access any community support? No. Was there any available?

SPEAKER_2
[00:21:59,752]No, there was none available, especially living in Walsall. I have to go to the hospital who has a special- who specializes in sickle cell, which is all the way in Birmingham. So, there's not much in Walsall at all.

SPEAKER_2
[00:22:12,152]Are you accessing any now? I don't know. Yeah, no. Alright.

SPEAKER_2
[00:22:18,102]Um, so, would you like to access some support? Obviously, you were referred to

us by, um, Amy. Yeah. And how has that been since we intervened?

SPEAKER_2
[00:22:33,502]It's been really good. Um, I've um... It's okay. Yeah, do you want to support me for a minute? Yeah. We have. Come on. Oh. Yeah. Can we take a break?

SPEAKER_0
[00:22:48,292]Kosovo

SPEAKER_2
[00:22:49,182]Eh. Oh, I'm sorry. You want a tissue? Mm-mm. No. No, I'm not gonna cry. Oh no.

SPEAKER_0
[00:22:55,242]Take your time.

SPEAKER_2
[00:22:56,502]Yes. Uh, did you know, I um we'll probably have to start again. Yeah, please. That's okay.

SPEAKER_2
[00:23:02,462]'Cause I wanted to mention because we want to highlight that, um, Plasma of Hope is supporting you. So, um, we'll just ask that again and just explain how the support has been. Uh, because I remember, you know, you might not want to share it, but when we, when we made contact, you were in a very bad place. But I'm so glad that, you know, we, we got somewhere.

SPEAKER_2
[00:23:26,352]And like you mentioned, not many people know about these sorts of services. Yeah. And yeah. You're doing good. Thank you. You're doing really good.

SPEAKER_2
[00:23:38,062]So, I'm just going to ask that again. Yeah, pretty good to go. Nah, do you want some water? Mm-hmm. C

SPEAKER_2
[00:23:50,762]I'm just trying to think of how to word it. Amen

SPEAKER_2
[00:23:53,702]See now just say it however. Yeah. So the question I'm going to ask again is, you know, about the community service out there around, like obviously there wasn't any. I myself have been in hospital for that long.

SPEAKER_2
[00:24:08,212]there's never been any community support and everything's a bit lame. So, just explain how you felt about that and the fact that there's nothing available for you as a young person, you know, especially

SPEAKER_2
[00:24:21,872]not being able to see people, your peers living, you know, with sickle cell and all that. Just pretty not good.

SPEAKER_0
[00:24:27,682]Also, there's no wrong or right way, you know. And also there's no rush. So if you want to take your time and think about the answer, do that. We've got the... we'll cut out whatever

we want to cut out. Okay.

SPEAKER_2
[00:24:39,022]until you've got time to think about it and then

SPEAKER_0
[00:24:42,322]say if anyone wants to say anything, you want to rephrase, there's no wrong or right.

SPEAKER_2
[00:24:46,402]All right. All right. Thank you. Yeah. Go.

SPEAKER_2
[00:24:50,742]So, I'm just going to ask that again. So, um, you've lived in Warsaw all your life. Looking back in the days when you were younger, was there any community support, any organization that your family could access in terms of support with sickle cell?

SPEAKER_2
[00:25:11,982]No, there was no community in Warsaw. Um, like I said, all it was all based in Birmingham. Um, it wasn't the easiest to get there to and from Birmingham as well. Um, sometimes we'd have to catch public transport, like the bus or train. So it was quite long.

SPEAKER_2
[00:25:33,812]Yeah. And currently, is there any community organization that is supporting you? yeah Okay, would you like to explain what kind of support you receive in England?

SPEAKER_2
[00:25:46,062]Um, so, um, it's, bulls

SPEAKER_2
[00:25:51,302]So, it's Classmates of Hope. Yeah. And you don't have to share anything. Um, it's up to you, but it would be nice for us to know how, you know, you were not in a good place, you needed lots of support with housing, with, you know,

SPEAKER_2
[00:26:09,872]financial benefits and all that. So you didn't know who to get in touch with that understood your situation, especially living with sickle cell. I mean you were quite isolated. Mhm It's up to you if you want to share that.

SPEAKER_2
[00:26:26,532]No. Yeah. Okay. Would you like that again? Yeah. You're doing good. You're doing really good. You are.

SPEAKER_0
[00:26:35,472]Yeah

SPEAKER_2
[00:26:36,792]So, is there any community support that is available to you at the moment? Yeah. Yes.

SPEAKER_2
[00:26:49,212]I don't know, I don't know what it is. I'm overthinking it. No, we'll move to another question. Don't worry. thinking I think we'll have a break for a little bit, yeah.

SPEAKER_0
[00:26:59,902]As I say, just let her speak. Nicole, you take your time and say how you want to explain, if you want to explain it. Do you know?

SPEAKER_2
[00:27:07,992]There's no rush. Yeah. He's just gonna edit whatever he needs to edit, right?

SPEAKER_0
[00:27:13,522]Yeah.

SPEAKER_2
[00:27:14,252]Mmm. Yeah. So, I'm even looking at this, I'm not going with this. I'm just asking as you respond, so. Okay, okay, don't worry about it. Just take your time. Okay.

SPEAKER_2
[00:27:29,902]Yeah.

SPEAKER_2
[00:27:34,842]So, um, the question, do you want me to remind you again? What support is available to you now?

SPEAKER_2
[00:27:43,282]Okay. Um, so the support that's available for me now is um...

SPEAKER_2
[00:27:55,282]Mmm... ahem. Um.

SPEAKER_2
[00:28:09,032]I was in a dark place and um

SPEAKER_2
[00:28:14,092]A neighbor got in touch with me and advised me to um get in touch with Mary Claire who works for Prisoner of Hope.

SPEAKER_2
[00:28:21,932]Um, ever since I've met Mary Claire, she's helped me a lot. Um, like, she's... oh my gosh. I think it's because I don't like being vulnerable.

SPEAKER_2
[00:28:35,932]It just feels... I know, I know. Oi, tudo bem?

SPEAKER_0
[00:28:41,782]Yeah. you want to protect yourself in certain ways and you don't want to give too much away. Yeah. Makes a lot of sense. Makes a lot of sense. So don't do that.

SPEAKER_0
[00:28:51,042]just if you want to say that that's as much as what you'd like to say about that, that's absolutely fine as well.

SPEAKER_2
[00:28:57,162]Okay, but if I say something, you're gonna edit that.

SPEAKER_2
[00:29:03,542]I'm not going to call any names, but um I'm currently supporting two other people who are the same age group as you. And they were shocked when I told them that they were the only ones.

SPEAKER_2
[00:29:18,712]because they feel that they were the only young people in that situation. Remember I gave you Shona's telephone number? Yeah. She's in a bad place.

SPEAKER_2
[00:29:29,692]and the fact that I told her about you, I'm gonna cry. I told her about you.

SPEAKER_2
[00:29:37,762]It's just been different. She's so lonely and she's somewhere I can't reach her.

SPEAKER_2
[00:29:46,202]And the fact that she spoke to you, she's just telling me how grateful she is to know that someone else is going through what she's going through, but it's not many people that she can talk with that understand. Yeah.

SPEAKER_2
[00:30:01,232]所以要老了。 And this thing we're doing is gonna let people know that they're not alone.

SPEAKER_2
[00:30:09,942]And the reason I'm doing this work was explaining to Ife that many people in my family wanted me to share my story about sickle cell. I've been living a lie for too long.

SPEAKER_2
[00:30:23,252]I had to stop. 'Cause I was embarrassed, I couldn't go out with my friends. E

SPEAKER_2
[00:30:31,402]I just used to get so angry. Why am I different? Because looking at you, you wouldn't tell me what's what's looking at me, you wouldn't tell.

SPEAKER_2
[00:30:40,962]but people don't understand what we're going through. And for me, that's what's important. And I don't care what people think.

SPEAKER_2
[00:30:52,412]I go through what I go through, I speak what I'm comfortable speaking about, and you don't have to.

SPEAKER_2
[00:31:01,912]But know that the more you share your story, the more it will help someone out there who thinks that they're alone. I'm going to be interviewing Shona Steph as well.

SPEAKER_2
[00:31:17,092]Um, as much as I'm looking forward to that, it's going to be quite emotional. Because she's attempted suicide twice. and I'm dreading interviewing her. But I need to.

SPEAKER_2
[00:31:34,262]Yeah And I don't know if that is in the switch.

SPEAKER_2
[00:31:39,622]Yeah. So, just say whatever you feel like. You don't have, you don't have to. If you don't want to, it's fine. But know that it's okay to be vulnerable.

SPEAKER_0
[00:31:56,782]Can I just say something as well? Yeah. Um, I don't have sickle cell, but I've been aware of it for many years.

SPEAKER_0
[00:32:07,072]And um one of the things that really bothers me is that the services and the support services available are not what they should be. So when you said earlier on about um going to hospital and the response, the kind of lack of response in a way.

SPEAKER_0
[00:32:22,582]the lack of awareness, like, that's another reason why what we're doing now is going to be important because we also want to make sure that health support services are better aware of what our experiences are.

SPEAKER_2
[00:32:36,682]Hmm

SPEAKER_0
[00:32:37,392]and can better respond to when crises occur or when any non-medical situation arises that you need some kind of treatment, it's not a flimsy treatment that's based upon lack of knowledge.

SPEAKER_2
[00:32:50,922]Yeah.

SPEAKER_0
[00:32:51,562]So, um, that's another aim of this. So anything that you contribute will be also contributing to us trying to raise awareness of the support services that are available.

SPEAKER_2
[00:33:02,132]Okay

SPEAKER_0
[00:33:02,982]to to to to yourselves

SPEAKER_0
[00:33:05,812]All right. And as I say also, there's no wrong or right. Um and if you do feel like there's something that you prefer not to answer,

SPEAKER_0
[00:33:16,122]that is absolutely fine. So every question that comes up, I'd prefer to not talk about that, is it a valid answer as well.

SPEAKER_2
[00:33:25,142]Yes. Okay. Thank you, please. No, that is so true. and yeah, highlighting what isn't available that should be available is key.

SPEAKER_2

[00:33:37,802]Because there's so much going into other conditions. There's not a lot going into sickle cell.

SPEAKER_2
[00:33:48,082]Okay, can I come back to that question?

SPEAKER_0
[00:33:50,672]Koschei

SPEAKER_2
[00:34:16,742]Uh-uh.

SPEAKER_2
[00:34:51,792]Can I come back to it?

SPEAKER_2
[00:34:55,522]Is that the last one?

SPEAKER_0
[00:34:57,312]next question

SPEAKER_2
[00:34:58,232]go to the next one. I think I'm going to get into something lighter. Okay. Yeah. Um.

SPEAKER_2
[00:35:09,492]I know you're a young person and you've got friends and, uh, have you always lived in Warsaw? Went to primary and secondary school in Warsaw?

SPEAKER_2
[00:35:23,152]Yeah. How has schizophrenia impacted your relationship with your friends? Um.

SPEAKER_2
[00:35:30,822]It's like a lot of activities that I couldn't do with my friends. Um, like if they wanted to go to a water park, I would have to be cautious about that. Um. Okay.

SPEAKER_2
[00:35:44,662]Do you feel comfortable discussing your situation with your friends? Um.

SPEAKER_2
[00:35:51,572]Not really, I don't really bring it up to them because I feel like um they won't really understand and

SPEAKER_2
[00:36:03,692]I only like to bring it up if I am in a crisis, then I'll talk about it. But if I'm not, then I'll try and avoid it. Yeah. If you could

SPEAKER_2
[00:36:15,972]speak to someone who's a younger person who lives with sickle cell. What advice would you give them?

SPEAKER_2
[00:36:39,102]to not be so hard on yourself when you're going through um these um crises um it takes time to heal um

SPEAKER_2
[00:36:52,872]just be patient and just be present in the moment and try not to dwell on the things that you're going through with the pain, um because it will pass over. Um.

SPEAKER_2
[00:37:09,162]Yeah. Yeah. Thank you for saying that. I don't know what else to say. Yeah, that's good, that's good. Have you ever met anyone older than you who's got sickle cell?

SPEAKER_2
[00:37:24,002]Um, yeah. How do you think their experience is different from yours? Do you have any ideas?

SPEAKER_2
[00:37:35,872]Well, to be honest, I've only come across yourself. Um, but I'm

SPEAKER_2
[00:37:49,552]That's fine, that's fine. I mean we've talked about accessing care in the hospital and the community and hospital in particular. Mhm.

SPEAKER_2
[00:38:00,852]and many people that we speak to talk about the healthcare professionals not having enough knowledge about sickle cell and

SPEAKER_2
[00:38:14,662]In what ways do you think they could do better? Um, sorry, what was the question again?

SPEAKER_2
[00:38:21,522]you know, you've talked about maybe going to hospital, the healthcare professionals not having enough knowledge, you feel like, you know, they don't understand you.

SPEAKER_2
[00:38:32,072]Um, what do you think could be better? What can you think of anything? How

SPEAKER_2
[00:38:40,092]um, probably having more community events that's related to sickle cell at the hospitals.

SPEAKER_2
[00:38:50,942]Um, probably, um, more education in schools about it.

SPEAKER_2
[00:39:02,342]Um, so the children and teachers are more aware of sickle cell and how it affects people who have sickle cell. Um,

SPEAKER_2
[00:39:14,002]We're coming towards the end, sorry. Okay. Um, I wanted to ask about what has helped you most in managing sickle cell physically and especially mentally.

SPEAKER_2
[00:39:27,242]Um, mentally being around family who generally look out for me and care for me.

SPEAKER_2
[00:39:37,712]and help me with my daily tasks around the house, um and like getting dressed as well if I do have a sickle cell crisis and I don't know, um

SPEAKER_2
[00:39:51,462]doing grocery shopping for me when I'm having a crisis. Um, because I'm... oh gosh.

SPEAKER_2
[00:40:03,872]He just mentioned going free shopping. Yeah. Well, what is your challenge with that?

SPEAKER_2
[00:40:11,922]Um, I can't really do the grocery shopping by myself if I'm having a crisis because if I have it in my leg, I can't really walk on it.

SPEAKER_2
[00:40:23,052]Um it's too intense and I lose my balance so I can't walk around. And you mentioned your family um...

SPEAKER_2
[00:40:36,872]Do you feel like your family understands your situation and gives you Yeah, because they've seen me in a crisis and they know how bad it can um affect me.

SPEAKER_2
[00:40:47,942]In your opinion, uh, I mean you don't have to answer this, what do you think still needs to change, um especially when it comes to sickle cell and mental health?

SPEAKER_2
[00:41:00,572]Um, especially in the hospitals, um when you have a crisis, um they just tend to just leave you. Um...

SPEAKER_2
[00:41:15,122]they give you your medication and they just go about their business. Well, I do understand that they have their duties that they need to do in the hospital.

SPEAKER_2
[00:41:22,862]but it's nice to have someone to talk to if your family's if your family isn't in there to visit you, because they only have a limited amount of time to visit you and spend time with you and to distract you from the actual pain that you're um having.

SPEAKER_2
[00:41:37,202]So, yeah, like having a nurse coming up to you and just having a conversation. Um, it helps a lot, it goes a long way because with the pain that you're in.

SPEAKER_2
[00:41:49,122]you're usually just in your head about it because you just can't escape the pain because it's just um sometimes the pain can be traveling or it can be throbbing or um

SPEAKER_2
[00:42:03,172]Yeah, so it's hard to, um, thank you. Yeah. Um, have you ever faced any stigma? Um, what do you mean?

SPEAKER_2

[00:42:15,352]So, um, I know in some communities Some people shy away from talking about sickle cell because there's stigma attached to it, like

SPEAKER_2
[00:42:28,012]if you're born with sickle cell, that means you're not going to be this person, you're going to die at a certain age, you can't do this, you, you know, you're not allowed to do that or have you ever faced or come across that?

SPEAKER_2
[00:42:42,442]Has anyone ever told you that because of your condition you aren't able to do certain things or you can't do that or you won't be able to, that stigma? Have you ever faced that?

SPEAKER_2
[00:42:56,082]I mean, maybe not. No, not really because I try to avoid bringing up that I have sickle cell because it's not... I'm kind of embarrassed to tell people that I have sickle cell.

SPEAKER_2
[00:43:08,582]Okay. 'cause they might treat me differently. Has anyone ever treated you differently? Um.

SPEAKER_2
[00:43:22,592]and just in primary school my younger ages, I felt like I was treated differently. Once one of my friends found out that I had sickle cell, she treated me differently. Um

SPEAKER_2
[00:43:35,662]How did that make you feel? Um, like I didn't want to open up about my condition again to anyone who, um, yeah.

SPEAKER_2
[00:43:48,112]Has that affected you? Did that affect you as you were growing up? Did you, you know, your confidence in telling... Yeah. When you were in secondary school, did you tell your friends about it?

SPEAKER_2
[00:44:00,052]Um, yeah, not until I had a crisis then I opened up about it. Otherwise, I'd just avoid it. I wouldn't just go out my way and say, oh yeah. Okay. Do you feel comfortable now?

SPEAKER_2
[00:44:13,652]Um, yeah, it's only recently I've started to become more accepting of my condition. Um, since I've been admitted into hospitals for the treatment, I've been more accepting of what...

SPEAKER_2
[00:44:27,652]of my condition, um, because before I used to just, um, stay in the house and deal with it behind closed doors.

SPEAKER_2
[00:44:37,292]Um, excuse me, but um I've realized that it's best to go to the hospital and to get the treatment from the doctors and nurses, um because it does speed up the healing process.

SPEAKER_2
[00:44:54,062]We just and we do encourage anyone who is really struggling and I know many people don't like hospitals but if it's unmanageable, it's always advisable to go to the hospital, call nine nine nine.

SPEAKER_2
[00:45:09,912]And just picking up on 999, have you ever had to call the ambulance? No. Okay, that's good. So, uh, my last question is if you're comfortable, we go back to that question. Mhm.

SPEAKER_2
[00:45:23,082]Um, think looking at when you were growing up, was there any support available to you and your family in the community? No, there wasn't any support.

SPEAKER_2
[00:45:37,052]So it's just you and your family managing. Um, looking at now.

SPEAKER_2
[00:45:47,002]Is there any support apart from the treatment you get from the hospital? Is there anything available in the community and are you accessing any of the support? Yeah, I am now. Um... I think the question is...

SPEAKER_0
[00:46:00,092]Could you tell us about the support that you received?

SPEAKER_2
[00:46:03,152]Okay. Um, so the support I receive now um is it's

SPEAKER_2
[00:46:16,722]I think I'm struggling on how to word it. So, I'll make it easy. Just explain how you got to get in touch with us. Oh yeah. Yeah. Um, what the situation was before you moved back. Sorry.

SPEAKER_2
[00:46:32,232]Um. So, I was introduced to Plasma of Hope by a neighbor. Um, since I've been introduced to the charity Plasma of Hope, um,

SPEAKER_2
[00:46:44,562]I've felt more seen and more supported since um I've since

SPEAKER_2
[00:46:52,722]cough

SPEAKER_2
[00:46:55,152]Um.

SPEAKER_2
[00:46:59,532]I felt more seen and supported and understood. Um and acknowledge in the journey that I'm in currently with um my sickle cell and accepting

SPEAKER_2
[00:47:14,272]Um, that I'm not the only one that's having to deal with the crisis. Um, I've learned so much about my condition and different ways to manage it.

SPEAKER_2
[00:47:27,482]um and different ways that I can get support from the community as well. um yeah.

SPEAKER_2

[00:47:39,482]Okay, okay. And do you feel, I don't know if this is an open and shut question. Do you feel that we need more community organizations to wrap it up?

SPEAKER_2
[00:47:53,652]can you just explain how that will help other people? Yeah, I do believe we do need more community um in regarding sickle cell.

SPEAKER_2
[00:48:05,832]But I have noticed that more people are becoming aware of it. Um

SPEAKER_2
[00:48:12,222]I've noticed on social media that there's a lot of um content creators who do have the condition sickle cell and they share their story um about it like

SPEAKER_2
[00:48:25,002]the times where they're having receiving treatment in the hospital and what they do to prevent um their crises

SPEAKER_2
[00:48:35,192]um and how they're overlooked in the medical industry, um in the medical industry as well. That's really important what you just said there, social media.

SPEAKER_2
[00:48:47,862]Mhm. Um, have you come across, you've obviously come across people that are sharing their stories about sickle cell. How does that make you feel?

SPEAKER_2
[00:48:58,452]Um, it's empowering 'cause it's made me accept that um my condition um even more.

SPEAKER_2
[00:49:08,882]and I'm kinda open to sharing my story as well. Um because for so long I've just kept it within and tried to avoid talking about my condition because

SPEAKER_2
[00:49:22,672]I feel like I don't want to put a damper on my mood. Um, cause I'm feeling so much pain and going through so much mentally as well when I have a crisis.

SPEAKER_2
[00:49:36,822]Um yeah. And um how do you feel about being part of this and sharing your story? I know it's been difficult. Yeah.

SPEAKER_2
[00:49:50,832]and we really appreciate you sharing your vulnerabilities with us. How do you feel about being part of this?

SPEAKER_2
[00:50:05,202]How do you feel about being part of this? Yeah.

SPEAKER_2
[00:50:10,142]Probably having more community events that's related to sickle cell at the hospitals. Um probably

SPEAKER_2
[00:50:21,072]um more education in schools about it. Um, so the children and teachers are more aware of sickle cell.

SPEAKER_2
[00:50:30,912]and how it affects people who have sickle cell. Um, yeah, we're coming towards the end, sorry. Okay. Um

SPEAKER_2
[00:50:41,582]I wanted to ask about what has helped you most in managing sickle cell physically and especially mentally. Um, mentally being around family who, um...

SPEAKER_2
[00:50:55,362]Generally look out for me and care for me and help me with my daily tasks around the house. Um and like getting dressed as well if I do have

SPEAKER_2
[00:51:05,272]a sickle cell crisis and I don't know, um doing grocery shopping for me when I'm having a crisis. Um

SPEAKER_2
[00:51:16,702]because um oh gosh. You just mentioned going shopping. Yeah. Wow.

SPEAKER_2
[00:51:29,582]What is your challenge with that? Um, I can't really do the grocery shopping by myself, um if I'm having a crisis because, um if I have it in my leg, I can't really

SPEAKER_2
[00:51:38,722]walk on it. Um it's too intense and I'll use my balance. So I can't walk around. and you you

SPEAKER_2
[00:51:49,822]mention your family. Um, do you feel like your family understands your situation and they give you Yeah, because they've seen me in a crisis and they know how bad it can um affect me.

SPEAKER_2
[00:52:04,982]In your opinion, uh, I mean you don't have to answer this, what do you think still needs to change? Um, especially when it comes to sickle cell and mental health.

SPEAKER_2
[00:52:17,782]Hmm. Um, especially in the hospitals and when you have a crisis, um, they just tend to just leave you. Um, they give you your medication and they just go about their business. Well, I do I do understand that they have their duties that they need to do in the hospital, but it's nice to have someone to talk to if your families if your family isn't in there to visit you because they only have a limited

SPEAKER_2
[00:52:27,972]amount of time to visit you and spend time with you and to distract you from the actual pain that you're having. So, yeah, like having a nurse coming up to you and just having a conversation.

SPEAKER_2

[00:52:39,642]Um, it helps a lot, it goes a long way because with the pain that you're in, you're usually just in your head about it because you just can't escape the pain because it's just um sometimes the pain can be travelling or it can be throbbing or

SPEAKER_2
[00:52:49,822]Yeah, so it's really hard to explain. So basically what happened was I was walking along the path and I saw a man walking along the path and I thought he looked familiar. So I started talking to him. He was wearing a red shirt and he had a white tie on. He was wearing a white hat and black trousers. He was wearing a black hat and black trousers. He was wearing a black hat and black trousers. He was wearing a black hat and black trousers. He was wearing a black hat and black trousers. He was wearing a black hat and black trousers. He was wearing a black hat and black trousers.

SPEAKER_2
[00:52:59,062]Oh, oh, yeah. Okay, that's good. So, um, my last question is if you're comfortable, we go back to that question. Um, it helps a lot, it goes a long way because

SPEAKER_2
[00:53:09,322]with the pain that you're in, you're usually just in your head about it because you just can't escape the pain because it's just um sometimes the pain can be traveling or it can be throbbing or

SPEAKER_2
[00:53:21,792]um yeah, so it's hard to um Thank you. Yeah. Um, have you ever faced any stigma? Um, what do you mean?

SPEAKER_2
[00:53:36,182]So, um, I know in some communities, some people shy away from talking about sickle cell because there's stigma attached to it, like

SPEAKER_2
[00:53:48,472]if you're born with sickle cell, that means you're not going to be this person, you're going to die at a certain age, you can't do this, you, you know, you're not allowed to do that or have you ever faced or come across that?

SPEAKER_2
[00:54:02,922]Has anyone ever told you that because of your condition, you aren't able to do certain things or you can't do that or you won't be able to? That's a stigma. Have you ever faced that? I mean, maybe not.

SPEAKER_2
[00:54:18,012]No, not really because I try to avoid bringing up that I have sickle cell because it's not, I'm kind of embarrassed to tell people that I have sickle cell. Okay. cuz they might treat me differently

SPEAKER_2
[00:54:33,172]Has anyone ever treated you differently? Um.

SPEAKER_2
[00:54:43,172]I'm just in primary school, my younger age. I felt like I was treated differently, but once my, um, one of my friends found out that I had sickle cell, she treated me differently. Um,

SPEAKER_2

[00:54:56,222]How did that make you feel? Um, like I didn't want to open up about my condition again to anyone who, um, yeah.

SPEAKER_2
[00:55:08,712]Has that affected you? Did that affect you as you were growing up? Did it, you know, your confidence in telling people in secondary school, did you tell your friends about it?

SPEAKER_2
[00:55:20,742]Um, yeah, not until I had a crisis then I opened up about it. Otherwise, I'd just avoid it. I wouldn't just go out my way and say, oh yeah. Okay. I have this condition. Do you feel comfortable now?

SPEAKER_2
[00:55:34,332]Um, yeah, it's only recently I've started to become more accepting of my condition. Um, since I've been admitted into hospitals for the treatment, I've been...

SPEAKER_2
[00:55:46,072]more accepting of what my condition is because before I used to just stay in the house and deal with it behind closed doors. Um

SPEAKER_2
[00:55:58,122]Excuse me, but um I've realised that it's best to go to the hospital and to get the treatment from the doctors and nurses um because it's

SPEAKER_2
[00:56:09,822]It does speed up the healing process. It does.

SPEAKER_2
[00:56:13,872]and we do encourage anyone who is really struggling and I know many people don't like hospitals but if it's unmanageable, it's always advisable to go to the hospital or call 999.

SPEAKER_2
[00:56:28,872]And just speaking up on 999, have you ever had to call the ambulance? No. Okay, that's good. So, um my last question is if you're comfortable, we go back to that question?

SPEAKER_2
[00:56:40,982]Mhm. Um, if you're looking at when you were growing up, was there any support available to you and your family in the community?

SPEAKER_2
[00:56:53,092]No, there wasn't any support. Okay. So it's just you and your family managing. Um, looking at now.

SPEAKER_2
[00:57:05,932]Is there any support apart from the treatment you get from the hospital? Is there anything available in the community and are you accessing any of the support? Yeah, I am now. Um... I think the question is... Yeah.

SPEAKER_0
[00:57:19,732]could you tell us about the support that you receive in the ward?

SPEAKER_2
[00:57:22,422]Okay. Yeah. Um, so the support I receive now, um, is...

SPEAKER_2
[00:57:35,772]I think I'm struggling on how to word it. No. So, I'll make it easy. Just explain how you got to get in touch with us. Oh yeah, totally. Um, what the situation was before you managed to make it... Sorry.

SPEAKER_2
[00:57:51,422]Um, so I was introduced to Plasma of Hope by a neighbor. Um, since I've been introduced to the charity Plasma of Hope, um, I've felt more seen and more supported since

SPEAKER_2
[00:58:03,732]Um, I've since um I felt more seen and supported and understood.

SPEAKER_2
[00:58:17,302]um and acknowledge it the journey that I'm in currently with um my sickle cell and accepting um

SPEAKER_2
[00:58:28,922]that I'm not the only one that's having to deal with the crisis. Um, I've learned so much about my condition and different ways to manage it. Um

SPEAKER_2
[00:58:42,322]and different ways I can get support from the community as well. Um, yeah.

SPEAKER_2
[00:58:54,082]And do you feel, I don't know if this is an awkward question, do you feel that

SPEAKER_2
[00:59:01,972]we need more community organizations to wrap it around and understand. Can you just explain how that will help other people?

SPEAKER_2
[00:59:11,032]Yeah, I do believe we do need more community in regarding sickle cell. But I have noticed that more people are becoming aware of it. Um I've noticed on social media that

SPEAKER_2
[00:59:25,592]there's a lot of um content creators who do have the condition sickle cell and they share their story um about it like the times where they're having

SPEAKER_2
[00:59:33,932]receiving treatment in the hospital and what they do to prevent um their crises is

SPEAKER_2
[00:59:45,712]Okay. Um, and how they're overlooked in the medical industry in the medical industry as well.

SPEAKER_2
[00:59:55,752]That's really important what you just said there, social media. Mhm. Um, have you come across, you've obviously come across people that are sharing their stories about sickle cell.

SPEAKER_2
[01:00:06,092]How does that make you feel? Um, it's empowering 'cause it's made me accept that um my condition um even more and I'm kind of open to sharing my story as well. Um, because

for so long I've just kept it within and tried to avoid talking about my condition because

SPEAKER_2
[01:00:15,542]I feel like I don't want to put a damper on my mood. Um, 'cause I'm feeling so much pain and going through so much mentally as well when I have a crisis. Um...

SPEAKER_2
[01:00:29,242]yeah. And um, how do you feel about being part of this and sharing your story? I know it's been difficult. Yeah. And we really appreciate you sharing your vulnerabilities with us.

SPEAKER_2
[01:00:40,332]How do you feel about being part of this?

SPEAKER_2
[01:00:48,322]Um, I'm good with you, and I'm happy to help you.

SPEAKER_2
[01:01:00,812]Yeah, yeah. I know what you mean, and I've been looking forward to this interview for a long time. It's been... it's been difficult. Yeah. And we really appreciate you sharing your vulnerabilities with us.

SPEAKER_2
[01:01:11,682]How do you feel about being part of this and just sharing your story? I know it's been difficult. Yeah. And we really appreciate you sharing your vulnerabilities with us.

SPEAKER_2
[01:01:25,732]How do you feel about being part of this? Um, I'm good with you, and I'm happy to help you. Um, so basically what I'm interested in is

SPEAKER_2
[01:01:34,982]in the hospital. Okay, yeah, thank you very much. Bye.

SPEAKER_2
[01:01:45,192]Bye-bye.

SPEAKER_2
[01:01:53,202]Goodbye.

SPEAKER_2
[01:01:58,942]Um, I'm good with you. And I don't mind if you want to ask about what has helped you most in managing sickle cell physically and especially mentally.

SPEAKER_2
[01:02:06,612]Um, yeah, mentally being around family who um generally look out for me and care for me and help me with my daily tasks around the house, um and like get dressed as well if I do have a sickle cell crisis and I don't know, um

SPEAKER_2
[01:02:16,582]doing grocery shopping for me when I'm having a crisis. Um, because um...

SPEAKER_2
[01:02:29,212]Okay. Yeah. Um, I'm going to ask about what has helped you most in managing sickle cell physically and especially mentally.

SPEAKER_2
[00:50:00,526]Um, it feels really good. I've never been a part of a community like this before, so it's nice to feel welcomed and just seen and accepted for who I am. Um, and knowing that I'm not dealing with this alone, and I know that other people have the same effect, um, same condition as me. Um, and just finding different ways to, um, cope with sickle cell and

SPEAKER_3
[00:50:29,586]Um That's really clever. That is, we've come to the end and that is a good place to end it.

SPEAKER_4
[00:50:38,476]Is there anything apart from if there is anything else you would like to say or add?

SPEAKER_3
[00:50:44,016]Okay.

SPEAKER_3
[00:50:46,346]No.

SPEAKER_2
[00:50:47,906]You've done really well.

SPEAKER_3
[00:50:50,106]Thanks.

SPEAKER_2
[00:50:51,626]That was really nerve-wracking.

SPEAKER_3
[00:50:53,316]It's okay. You did really well. A single sustained musical note played on a piano or keyboard.

SPEAKER_2
[00:50:56,166]Thanks.

SPEAKER_3
[00:50:58,336]You're welcome. I was just looking at the first thing on my to-do list I've got here. You make me cry and understand what you've been going through all by yourself.

SPEAKER_3
[00:51:14,436]Thank you.

SPEAKER_3
[00:51:18,476]Don't you forget your daddy.

SPEAKER_2
[00:51:21,126]Yeah.

SPEAKER_3
[00:51:23,176]Yeah, thank you. C

SPEAKER_2

[00:51:38,406]Honestly, I feel like the camera, with all eyes on me, is too much. I felt like I was overthinking it.

SPEAKER_3
[00:51:50,356]What was behind the camera? You're in front of it.

SPEAKER_3
[00:51:56,026]Yeah.

SPEAKER_4
[00:51:58,646]But um, as you say, you're doing really well. charity