MaryAnne.wav

Sickle Cell Patient Experience and Healthcare Advocacy Report

Summary Of Speaker Contributions

MaryAnne (SPEAKER 0): Provided a comprehensive account of her life as a sickle cell patient, spanning her diagnosis in Cameroon to her current experiences in the UK. She highlighted the systemic challenges of navigating healthcare systems, the emotional burden of chronic illness, and the difficulties of single parenting while managing health crises. She emphasized the necessity of self-advocacy and the importance of community support groups.

Marie Claire (SPEAKER 1): Representing the organization "Plasma of Hope," she facilitated the interview as part of the "Sickle Cell Stories Then and Now" project. Her contributions focused on documenting patient experiences to identify gaps in NHS care, mental health support, and the overall visibility of the condition within the healthcare system.

Key Points And Decisions

Healthcare Systemic Gaps: Both speakers agreed that there is a persistent lack of awareness among paramedics and A&E staff regarding sickle cell, which frequently results in delayed treatment, bias, and the dismissal of patient pain.

Mental Health and Support: Marianne identified a critical lack of immediate mental health support, noting that access is often contingent upon being involved with a charity rather than through standard NHS pathways.

Parenting Challenges: It was established that there is a significant gap in support for single parents with sickle cell, particularly regarding childcare during emergency hospitalizations.

Stigma and Advocacy: The participants agreed that the stigma surrounding sickle cell prevents many patients from seeking help. They decided that sharing personal experiences is essential to educate younger patients and push for better institutional training.

Next Steps And Action Items

Plasma of Hope (Marie Claire): Committed to utilizing the gathered testimonies to advocate for improved NHS training protocols and to highlight the necessity of integrated mental health support for sickle cell patients.

Marianne: Committed to continuing her involvement with support groups and mentoring younger patients to help them navigate the healthcare system and overcome the shame associated with the condition.

SPEAKER 0
[00:00:00,354]That's how she knows.

SPEAKER 1
[00:00:01,824]Marian

SPEAKER 0
[00:00:03,414]Hmm It's just me here.

SPEAKER 1
[00:00:05,134]Maria

SPEAKER 0
[00:00:05,914]C

SPEAKER 1
[00:00:08,994]Hi, good morning, Marianne.

SPEAKER 0
[00:00:11,514]Um, good morning.

SPEAKER 1
[00:00:13,034]How are you today?

SPEAKER 0
[00:00:15,214]Mmm, okay. not so bad

SPEAKER 1
[00:00:17,954]So thank you for allowing us to do this interview. Um my name is Marie Claire and I'm here with Effy. We're from Plasma of Hope um under the project um Sickle Cell Stories Then and Now. So we want to just ask you a few questions about life with sickle cell, your experience living with sickle cell and we're going to be asking you a couple of questions. Um you have signed a consent and you've given us permission to ask you these questions but if at any point in time you don't feel comfortable answering any of these questions, please let me know.

SPEAKER 1
[00:00:58,214]Okay

SPEAKER 0
[00:00:58,824]Okay, let's go.

SPEAKER 1
[00:00:59,934]Right, I'm going to start with diagnosis and early life with sickle cell. So, when and where were you first diagnosed with sickle cell?

SPEAKER 0
[00:01:12,304]Oh. Um actually I'm a Cameroonian, so I was diagnosed in Cameroon at the age of four. My mom told me I was diagnosed at the age of four in Bamenda, Northwest Province.

SPEAKER 1
[00:01:27,104]Okay. And what was it like growing up and living with a condition?

SPEAKER 0
[00:01:31,374]in Cameroon. It was really, um, my early days most of the time I was struggling with school education and playing, just normal day-to-day life was very difficult and different for

me because of the weather.

SPEAKER 0
[00:01:49,164]The fact that the treatment, the hospitals we used to go there were not very close to home. So we had to travel a long way to go to the hospital and most of the time I was having crises like almost every month or twice a month.

SPEAKER 1
[00:02:04,034]A single, sustained musical note.

SPEAKER 0
[00:02:04,584]It was really stressful for myself and my parents.

SPEAKER 1
[00:02:08,904]Okay Um, so for the sake of this interview, can we just ask how old you are?

SPEAKER 0
[00:02:17,324]I'm five, I'm going to be fifty-two next month.

SPEAKER 1
[00:02:22,204]Okay, that's amazing. Uh we're going to get to that uh in a minute. Um was there much awareness, um understanding sickle cell when you were young?

SPEAKER 0
[00:02:33,314]No, not at all. Actually, uh, there's a stigma about having sickle cell. Most people don't actually know if it's just a normal illness. People back home they'll think that uh maybe it's witchcraft or your parents did something and you have a curse. So a lot of people you have to try to, my early days as long as I can remember, I used to hide, uh, I used to be shy, not telling people that I'm a sickle cell patient. I wasn't bold enough to express myself. My parents all the time they'll be like, why is your child always sick?

SPEAKER 0
[00:03:11,874]Uh, why is she always in the hospital? Oh. There was no clear explanation because people did not actually know a lot. Even now, I don't think there's um a lot of awareness about sickle cell even back home.

SPEAKER 0
[00:03:26,354]Hmm African

SPEAKER 1
[00:03:28,304]Thank you. Thank you for saying that. And um, yeah, I think there is still a lot of lack of awareness. And you currently live in the UK and you've lived here for...

SPEAKER 1
[00:03:42,664]a very long time. Yes. But it is my understanding that you moved, you you you you you moved from Cameroon to um to Europe. Yeah. And before coming to the UK you were staying in Ireland. Is that correct?

SPEAKER 0
[00:04:01,744]Yes

SPEAKER 1
[00:04:02,584]How was it in Ireland in terms of

SPEAKER 0
[00:04:05,604]Okay, that will take us back to about nineteen ninety-nine, two thousand. I left Cameroon, went to the Netherlands, and then to Holland. That's where I met my ex-husband.

SPEAKER 0
[00:04:20,254]So, there I stayed there for two years, then um it wasn't actually, I didn't like to stay there because of the language barrier. Then I moved to Dublin, Republic of Ireland. But I think I had a few crises then. I think I was 27 when I moved to um Holland. It was then also, a lot of people did not actually know, but I was lucky, the hospital I went to, there were some few Africans or black doctors that they knew about sickle cell. They took care of me.

SPEAKER 0
[00:04:57,194]I was not having crises then as much as I used to have when I was younger. So the few times that I had crises, they they knew what to

SPEAKER 0
[00:05:04,924]to do. That's the first time I tried uh oramorph or morphine. I had never tried it so you can imagine from my uh young age I was just taking uh like paracetamol, ibuprofen for pain medication. It wasn't actually doing much.

SPEAKER 0
[00:05:23,944]but

SPEAKER 1
[00:05:29,534]Sorry.

SPEAKER 0
[00:05:30,804]cough

SPEAKER 1
[00:05:33,334]Sorry.

SPEAKER 0
[00:05:34,804]Sorry. You need water.

SPEAKER 1
[00:05:37,604]I'm actually recovering from a cold. Mmm, I hope so.

SPEAKER 0
[00:05:41,964]Heh

SPEAKER 1
[00:05:42,544]I'm not gonna pass it on.

SPEAKER 1
[00:05:45,704]Cough

SPEAKER 0
[00:05:47,604]Sorry, could you give me some water? Um, actually I should have brought my Oh, just take some. Hello cool

SPEAKER 1

[00:05:56,204]Oh no no no no.

SPEAKER 0
[00:05:57,124]Okay Sorry. Adiós.

SPEAKER 1
[00:05:59,484]Yes, open it.

SPEAKER 0
[00:06:00,664]Sorry, sorry, sorry. Okay, let's begin.

SPEAKER 0
[00:06:07,394]Sorry, are you doing an activity or coffee?

SPEAKER 1
[00:06:10,714]No, no, it's okay. We're just going to leave that running. and watch it.

SPEAKER 0
[00:06:15,144]Yeah

SPEAKER 1
[00:06:15,584]one

SPEAKER 0
[00:06:19,914]Sorry.

SPEAKER 1
[00:06:21,344]Do you want that?

SPEAKER 0
[00:06:23,004]Yeah, that's in the morning.

SPEAKER 1
[00:06:25,414]Twenty-six

SPEAKER 0
[00:06:27,554]Thanks. Thank you.

SPEAKER 0
[00:06:38,424]Das ist besser.

SPEAKER 1
[00:06:40,464]Thank you. Sorry, where were we?

SPEAKER 0
[00:06:44,104]어, 머리 좀 더 잘랐는데.

SPEAKER 1
[00:06:47,124]Yes.

SPEAKER 0
[00:06:49,204]Don't move.

SPEAKER 1
[00:06:50,684]Hello. Um, actually we can just move on. Uh we were talking about the experience of

SPEAKER 0
[00:06:56,034]of the medications I was having

SPEAKER 1
[00:06:57,854]Yes, yes, yes. And that was the first time you had morphine. Ja, in Ordnung. And um what led you to move to the UK?

SPEAKER 0
[00:07:11,464]Oh. Yeah, after I left Holland, because of the language barrier, I went to Dublin, Ireland. So I stayed there, and had the kids. I stayed there for like 15 years.

SPEAKER 1
[00:07:25,094]Oh.

SPEAKER 0
[00:07:25,724]Then unfortunately, I was going through a divorce, so I just decided to move to the UK.

SPEAKER 1
[00:07:33,084]How did you experience, you know, how did you experience managing sickle cell change after moving to the UK? So what part of the UK did you move to?

SPEAKER 0
[00:07:45,694]I moved to I first when I left um Dublin I went to Southampton. So there it was okay.

SPEAKER 0
[00:07:54,574]they were managing it. I had a good consultant, um he was very patient with me. I met other sickle cell patients there. So it was, and I had a sickle cell nurse that I could talk to anytime that I wanted. So that was different from Dublin because in Dublin we don't have that. You don't have a sickle cell nurse that you talk to. Yeah, you just go to the doctor or to the hospital. So the UK was different. I think I realized that a lot of people knew much more about sickle cell than in Dublin. Dublin's a small country.

SPEAKER 1
[00:08:28,814]Yeah.

SPEAKER 0
[00:08:29,394]So, the experience of moving to um Southampton was good.

SPEAKER 1
[00:08:33,704]Yeah, that actually leads to my next question. Did you find the UK healthcare system more equipped to support you?

SPEAKER 0
[00:08:40,814]To an extent, I would say yes, if I'm comparing it to where I was coming from.

SPEAKER 1

[00:08:45,354]Okay

SPEAKER 0
[00:08:45,834]It was.

SPEAKER 1
[00:08:46,704]and whether any challenges accessing care after relocating. Did you have any problems?

SPEAKER 0
[00:08:54,454]It was actually not that difficult, but for the first time I had to go look for a GP. You have to first of all register with a GP, then you get a referral to see the hematologist or... So it's a process, but although it's yeah, there is um it wasn't that bad.

SPEAKER 0
[00:09:15,484]since

SPEAKER 1
[00:09:16,554]So, um, we're going to talk about some of the complications that you faced and I know you've experienced multiple complications.

SPEAKER 1
[00:09:26,224]uhm with sickle cell. Would you be open to sharing how some of these complications are or have been and how you've ex- this has impacted your life?

SPEAKER 0
[00:09:40,674]Yes, sure. I think a part of the normal sickle cell crisis that you have with normal blood transfusions, I had um Bell's palsy when I moved to the UK.

SPEAKER 0
[00:09:54,904]I had Bell's palsy. I did not even know what that was. Went to the A&E. I thought it was a stroke that I had, but I went to the A&E, I went to hospital and they diagnosed that it was Bell's palsy. So I had some antibiotics and luckily that one cleared off after about a month or three months, I'll say.

SPEAKER 1
[00:10:23,224]Yep, no, that's fine. And how were those complications handled in the past compared to how they've been managed now? I know you're still having some challenges, you've just had um an operation on your shoulder. How would you say um things were being, you know, managing complications of sickle cell back then? And this is what we're talking about in the UK, back then and how they are now. How long have you been in the UK?

SPEAKER 1
[00:10:54,414]Since you're from Ireland?

SPEAKER 0
[00:10:56,184]About ten years.

SPEAKER 1
[00:10:57,334]Okay, yeah. So...

SPEAKER 0
[00:10:58,704]So, yeah, when I moved to the UK, you had to, I think, like in Southampton, a lot

of people were not really, um, they don't actually have, should I say knowledge? They were not actually, um, well informed about sickle cell, I would say. They had to either refer you to another doctor who knows about it or things like that. But when I moved, I had a series of complications. Apart from Bell's palsy, I've had AVN.

SPEAKER 0
[00:11:31,014]I've had a bit of a blood clot. I had a blood clot in Southampton. That was not really good because I wasn't, I've been, I was going to the hospital over and over for close to six months, telling them how I'm feeling, I'm feeling weak, I'm feeling...

SPEAKER 0
[00:11:47,974]exhausted

SPEAKER 0
[00:11:48,834]I'm very tired. They are always referring it back to, oh, you're a sickle cell patient, you're a sickle cell patient. So until there was a day I couldn't sleep, I couldn't breathe. I did an MRI scan which showed them, I did an X-ray, all those things. It showed but unfortunately my consultant was on holiday. So they did not follow up. So it got to a stage after a week or two that was during COVID period.

SPEAKER 0
[00:12:17,974]I said I went back to the hospital then they saw that, um, it had shown on one of my scans that I had a blood clot so they started treating it. I wasn't really happy then because it's something I was complaining about but they'll always tell you, just the fact that you're a sickle cell patient, they'll always, no matter what you complain about, they'll say, "Oh, it's sickle cell." Which is not good because there are other illnesses that you can have that are not sickle cell, but it won't be picked up on time because they are assuming that you're a sickle cell patient because of complications of sickle cell.

SPEAKER 1
[00:12:52,404]Yeah.

SPEAKER 1
[00:12:52,904]I was just going to ask that because a lot of people that we've interviewed have felt that, you know, upon presenting various complications that they live with, um, clinicians or hospitals are not taking them serious because they're assuming that it's sickle cell. Yeah. And is that the same way you felt?

SPEAKER 0
[00:13:17,804]Yes, exactly the same. So I said, there was a time I told the doctor even, no, don't just treat me as a normal person or as a normal individual. Don't always look at me as a sickle cell patient. He said, oh no, we can't do that because you're a sickle cell patient. I said, yeah, I know, but when you put that at the forefront, you won't see the other things because all your mind is, oh, she's a sickle cell patient. Just look at it as if it's a normal person complaining and we work from there.

SPEAKER 1
[00:13:47,414]Thank you. Do you feel that better awareness or earlier intervention could have changed things?

SPEAKER 0
[00:13:54,724]Of course. Of course.

SPEAKER 0
[00:13:55,884]any intervention would have changed it. Just the fact that, for example, the process also, if you have a consultant and the consultant is not around, and your X-ray or your results, they come up with something serious. Who is supposed to follow? They have to, it has to be, um, or there has to be a process in place for somebody to pick that up and follow up. They knew and they saw it the day I did the scan. Why did they not send it, if they realized that he wasn't around, why did they not send it to somebody else?

SPEAKER 1
[00:14:25,434]Thank you. So, we're going to look at mental health and emotional impact. So

SPEAKER 1
[00:14:35,984]How has living with sickle cell affected your mental health and emotional well-being over the years? And I know this is, I'm sure this is a question that you've been asked.

SPEAKER 0
[00:14:47,304]Yeah.

SPEAKER 1
[00:14:48,124]quite so often

SPEAKER 0
[00:14:50,024]Yeah. Yeah, um, there's a lot. I don't even know where to start.

SPEAKER 1
[00:14:55,084]So, can I make it make it um let's break it down because it's quite broad. Yeah. So, uh something I picked up, you said uh you left after you divorced.

SPEAKER 0
[00:15:08,194]Yes.

SPEAKER 1
[00:15:09,214]How was it being a wife?

SPEAKER 0
[00:15:13,894]Okay

SPEAKER 1
[00:15:15,054]as a sickle cell patient at the same time. if if you're not comfortable talking about any of that, please

SPEAKER 0
[00:15:22,474]No, it's okay. Um, it's kind of stressful, I would say. It's not easy. It's

SPEAKER 0
[00:15:34,464]It's, I would say it's stressful because you try to do the things you have to do as a wife, take care of the children, you are doing your best, but at the same time, you have crises in between. And managing your crises and managing your day-to-day, uh, chores is, uh, it's not easy because you will say, there are times you will say, oh, I'm not feeling well. Should I just tell my husband that I'm not feeling well? Then you say, no, oh, they will judge me that I'm not good enough to be a wife.

SPEAKER 0

[00:16:06,354]Let me just push and do what I'm supposed to do as a wife and at the same time you're doing what you have to do to take care of yourself, it's you you are under stress, under stress and nobody can actually understand how stressful it is because every day it's like your energy levels are low, you try to tell them I'm tired, it's like you're complaining or you're a lazy person, which is not good.

SPEAKER 1
[00:16:31,734]Did you feel like you had anybody to talk to about this at the time?

SPEAKER 0
[00:16:36,894]Not really. I think that is not like, like I said, most of my marriage life I was in Dublin.

SPEAKER 0
[00:16:45,334]It wasn't, I was just talking once in a while to my GP, although she advised me to like to talk to family members or talk to other people, but I didn't have to go through counseling or. But in the UK I think it's better I'll say.

SPEAKER 0
[00:17:00,774]because I've had uh sessions, counseling sessions like three different times when I've been, you know, going through difficulties.

SPEAKER 1
[00:17:09,934]Was mental health support ever part of your treatment? Either in Ireland or you've just mentioned the UK. Yeah. So you've accessed mental health support in the UK? I have. Yes, I have. And has that helped?

SPEAKER 0
[00:17:25,714]Ja, ich weiß.

SPEAKER 0
[00:17:27,214]I would say to an extent it has helped, especially when I'm going through whatever I'm going through at that point in time. If there is early intervention or I have somebody to talk to at that point in time, it will help. But I've realised that when you apply or you try to talk before the help actually comes, it doesn't. On two different occasions I have not had it the time I actually needed it. You come maybe later on, maybe a month or two later on, but not immediately when I'm going through the issues I'm going through.

SPEAKER 1
[00:18:05,094]And do you think it would have been better if you had received the support when you asked for it?

SPEAKER 0
[00:18:11,724]Yes. Okay.

SPEAKER 1
[00:18:13,044]Right. Um, so that's something that we have to highlight. And how do you cope with the emotional toll of living with chronic complications? I mean in your everyday life.

SPEAKER 0
[00:18:26,394]I know especially in the UK, hmm the first thing is to even access support.

SPEAKER 0
[00:18:33,994]If you don't, if you are not lucky enough, uh for example myself, having to know

the charity I'm working with, Plasma of Hope. You go to the GP, they will tell you it's quite a long process. You don't even know, um there is no particular person to signpost you. If you go to Citizen Advice, they'll say, oh go online and check. If so, if you are not lucky enough to be working with a, with an NGO or with an organization, it's really difficult. It's really difficult.

SPEAKER 1
[00:19:07,214]Do you think this is something that the NHS has to bring on board because we've spoken to so many people who are really struggling to access mental health support?

SPEAKER 1
[00:19:19,374]and um, have you ever seen a clinical psychologist via your hematologist?

SPEAKER 0
[00:19:32,654]Mmm

SPEAKER 1
[00:19:34,254]Is that something that has been provided to you?

SPEAKER 0
[00:19:36,894]No. No.

SPEAKER 1
[00:19:38,684]And I think that's something that's important for every sickle cell patient because what we tend to hear like what you've explained, you know, if you're not involved with a charity

SPEAKER 0
[00:19:49,274]Yeah

SPEAKER 1
[00:19:49,904]It's very difficult to access support. Yeah. And um...

SPEAKER 0
[00:19:53,874]There was a time I actually spoke to my GP. I was going through a stressful situation or he said, oh, you have to go online and self-refer yourself. Which is another thing. If you are not being referred by a doctor or a charity, it takes time, you know.

SPEAKER 0
[00:20:11,904]Yes, absolutely.

SPEAKER 1
[00:20:12,964]It does, it does. Thank you. Thank you for sharing that.

SPEAKER 1
[00:20:18,874]If I may just ask, how do you think your mental health is at this point in time?

SPEAKER 0
[00:20:25,834]there is always one thing or the other, especially financially because since I had my... I have a shoulder replacement. I had a shoulder replacement and since then I've not been able to go back to full-time work. So it's actually the finances, no matter how you try to manage it, is not enough.

SPEAKER 1
[00:20:45,574]Okay.

SPEAKER 0
[00:20:46,614]So financially. There are things that are always coming up, the kids, uh, if I can... it's a struggle, I would say.

SPEAKER 1
[00:20:55,214]Thank you. And um moving on to parenting and family life. Um... uh what was it like raising children as a single parent while managing sickle cell?

SPEAKER 0
[00:21:09,474]Wow C

SPEAKER 0
[00:21:13,274]that was really, that period was really, really stressful but I thank God.

SPEAKER 1
[00:21:19,294]If I may ask, how old are your kids?

SPEAKER 0
[00:21:21,414]Um, the first is 23 and the second one is 19 now. Right. So they're quite young. Yes, but when I was going through the divorce, I think the boy was around nine years old and the girl was around twelve. And I was working then. So what I used to do is, I was doing a night shift. I was working with One Charity for homeless people.

SPEAKER 1
[00:21:45,204]So I'll have to Yeah, good. We're good.

SPEAKER 0
[00:21:51,624]Okay. I'll have to either put cameras in the house even if I'm leaving them with other people, just to see, just to monitor them what is happening. Which is not, it's not an easy thing. Most of the time you're at work, you don't concentrate. Then just the stress of driving here and there, you are tired but you still have to, there are bills to be paid.

SPEAKER 1
[00:22:13,264]Absolutely Absolutely And um, and how did your condition affect your ability to care for them, especially during a crisis?

SPEAKER 0
[00:22:23,394]Yes. Um, I was lucky enough, I had friends that were living around me, but I think from my experience I would say there should be support in place for sickle cell patients or sickle cell moms.

SPEAKER 0
[00:22:38,814]that in case of you or in case of a situation that you have a crisis, there is support there to actually take care of the kids. Because on the other hand, you are going to the hospital, you are not concentrating to get well because you are thinking, what are the kids doing now? Who is taking care of them? Are they safe where they are? Yes. So I think if there is um support for that, that if you have children and you are a sickle cell patient, when you're having a crisis and going to the hospital, what happens to the kids, especially when they are so young?

SPEAKER 1
[00:23:08,164]So you think there's a gap there?

SPEAKER 0
[00:23:10,284]There is a gap there, I would say.

SPEAKER 1
[00:23:11,724]single parent

SPEAKER 0
[00:23:12,784]Yes, because if I did not have friends around, what would I have done? Most of the time that I'm in the hospital for a week or so, the kids are still very young.

SPEAKER 1
[00:23:22,424]It's very important. Thank you for sharing that. Uh, did your children understand your health needs growing up, and how did they support you? Do you understand? Did you understand that?

SPEAKER 0
[00:23:34,804]Yeah, I had to tell them from when they start, say from the age of five, six, because they would always see me, oh, I'm not feeling well, they would ask questions. So I had to tell them and even educate them on how it would affect them in future. So I had that conversation with them. So growing up, I think they knew, they understood the situation.

SPEAKER 1
[00:23:57,034]Okay. And...

SPEAKER 1
[00:24:02,674]What has helped you feel less alone and supported over the years? I know you've mentioned, um, the support that we're giving you as a charity.

SPEAKER 0
[00:24:13,774]Yeah.

SPEAKER 0
[00:24:16,674]Um, friends and family, I would say.

SPEAKER 0
[00:24:20,814]friends and family and church group although they don't actually go because it's not something you just tell anyone you should be comfortable before explaining it to maybe the people around you. So it's that one is stressful if you don't have, say for people who don't have families around.

SPEAKER 1
[00:24:39,174]Yes.

SPEAKER 0
[00:24:39,744]Who do you talk to? instinct. Yeah.

SPEAKER 1
[00:24:42,164]Do you think there's enough support systems in place in the NHS for

SPEAKER 0
[00:24:49,304]Merci. Say what? No, I don't think so. We need more.

SPEAKER 1

[00:24:52,294]Venezuela

SPEAKER 0

[00:24:53,004]yeah, you need more because even uh I don't want to go very deep into that because at times you go to the hospital, if it's not your main hospital, you struggle. There was a time I went to visit a friend, I had a crisis, I went to the hospital. Because I could walk to the ambulance. When I went to the hospital, I couldn't walk that distance by the time we got to the hospital. And the uh ambulance people crew, they thought I was pretending. They were forcing me to walk. I said I couldn't walk. They said, but you walked to the ambulance.

SPEAKER 0

[00:25:30,274]I say yes. So I think even within the NHS, you see, there is a gap. They still need to train most of their staff. They don't know about it.

SPEAKER 1

[00:25:39,504]Thank you for bringing that up. And um we're just going to stay there for a bit. So, um what is your what and what your experience of accessing um care in the UK is very different across the region. So, yeah. So, you're currently receiving care in Wolverhampton and you feel that if you go away from Wolverhampton

SPEAKER 0

[00:26:01,924]Yes.

SPEAKER 1

[00:26:02,684]Because they don't understand you.

SPEAKER 0

[00:26:04,664]Yes, if you go away from Overhampton, they will because they don't have your file, they don't understand sickle cell. You are not talking to a hematologist directly when you go into A&E. It's completely different. The treatment you receive will be completely different.

SPEAKER 1

[00:26:20,944]Yeah

SPEAKER 1

[00:26:23,274]Thank you for mentioning that. Um, do you feel sickle cell is more visible or better understood in the UK compared to Ireland?

SPEAKER 0

[00:26:36,734]To an extent, I would say then anyway, it's a long time now, but when I was in Ireland, a lot of people did not actually know, they had not even heard about sickle cell. But the UK, because a lot of Africans and um Asians in the UK, I think they know. They are, but not everyone because even in the NHS, at times you go to the hospital, even some of the nurses have never seen a sickle cell patient.

SPEAKER 1

[00:27:03,204]Okay. I'm just going to pick up something you mentioned about the ambulance. Over the years, you have accessed the ambulance service.

SPEAKER 1

[00:27:12,844]How do you feel about the ambulance service to patients with sickle cell when you call them? How do you think it has been back then and now? Is it any different?

SPEAKER 0

[00:27:27,424]I think with the ambulance people, when you call them, the people at the switchboard, I think they know what sickle cell is. But the paramedics, the paramedics that are actually coming, some of them don't know because the way they treat you, you know they don't even know what they are dealing with.

SPEAKER 1

[00:27:49,524]and is that would that is that still the same now and in the past

SPEAKER 0

[00:27:55,824]Yeah, I'm talking about, yes, in the UK. Yeah. Even when I was in Wolverhampton, some of them, some of the paramedics, they didn't actually know. Some of them, they are actually informed, well informed about

SPEAKER 1

[00:28:09,514]Okay

SPEAKER 0

[00:28:10,014]sickle cell, but you get to know by the way they treat you. Some of them would think, oh, you are just exaggerating, it cannot be that painful. I remember there was a time I even asked for the for the gas, the

SPEAKER 1

[00:28:22,444]Kathleen

SPEAKER 0

[00:28:23,394]Yes. It was like, oh no no no, we have just one now. Oh, we can't give you now. I said, I need it. I need it. He said, no, we'll be there very soon. just wait we'll be there

SPEAKER 0

[00:28:34,784]the moment we even when they give you it's like they are just in a haste to take it off you so

SPEAKER 1

[00:28:41,984]So there's that lack of understanding within the paramedic service. So we're going to um ask you about accessing accident and emergency service.

SPEAKER 0

[00:28:56,184]Okay

SPEAKER 1

[00:28:56,764]Yes, so how has your experience been? Um I know you've visited um hospitals across the country.

SPEAKER 1

[00:29:04,314]Um, back then now, um, how has your experience been? Do they have full understanding when you present to any?

SPEAKER 0

[00:29:14,854]Back then, like when I was in Southampton, I used to spend hours waiting. When I go into A&E, you have to spend hours waiting for your turn, you go through the normal process, which is not supposed to be like that. But somewhere along the line, I had a care plan.

SPEAKER 0

[00:29:36,034]So, that helps actually at times. Some people will actually look at your care plan and follow the rules and regulations or what is written on your care plan. But some people will be like, oh, no, we are very busy now. Like the last time I was admitted, even in Midland, even though I had a care plan, it was like they took the care plan, but they kept me there for more than an hour.

SPEAKER 0

[00:30:03,594]for about two hours, they actually kept me there. And I mentioned it there that I have a K plan. Please, you people should check on the system. But they still kept me waiting. Oh that oh we are busy. The guy was stro- out. Oh my god.

SPEAKER 0

[00:30:18,834]I told this person, this doctor, sorry, that I'm in pain. I'm in serious pain. I have a care plan on the system. He said, oh, look at it. But he was struggling.

SPEAKER 0

[00:30:31,374]He was asking me to do both for him and because he was struggling to do an HIV test.

SPEAKER 0

[00:30:37,774]I was like, is there a reason for that now? He said, oh no, it's just a normal process in ANE. I said, I've never been asked to do it. I said, I don't have a problem with that. I do it with the GP. But now, I just need to have something. He said, we'll deal with that. Then finally left me there for about two hours. And when I started complaining or started, you know, like calling for attention, then he came now, oh, we are sorry, we are sorry. They had forgotten about me completely. And just by doing that, under normal circumstances, I would have stayed in the hospital for three days if they had seen me the moment I went there.

SPEAKER 0

[00:31:17,994]I had to stay in the hospital for like one week because the pain had, you know, I did not take the pain medications on time. And when you don't do that, it will prolong your hospital stay.

SPEAKER 1

[00:31:32,914]Thank you. Thank you. that's really, that is really something. And um, how would you say the experience is now accessing ANE?

SPEAKER 0

[00:31:42,494]I think it depends on the day, the day you are there because there are some days that you go, they follow the care plan. You see, uh within 30 minutes they give you whatever they attend to you. But there are days that it depends who you are meeting there, they can leave you there for two hours. So which means all of them are not actually aware of or know how important the care plan is.

SPEAKER 1

[00:32:08,924]Yes Thank you. And have they always followed the care plan?

SPEAKER 0

[00:32:13,324]Some of them, not all the time.

SPEAKER 1

[00:32:16,394]All right, thank you. That was really, really informative. Ähm

SPEAKER 1
[00:32:25,224]What would you say has stayed the same or still needs to improve?

SPEAKER 0
[00:32:32,204]What has stayed the same and needs to improve, I would say is that, um, people don't actually understand or know how severe sickle cell is. No matter how you try to explain, it's only a sickle cell patient that will understand and know what you're going through. That's why you see more sickle cell patients when they meet, they become friends automatically because they know what they are going through. But no matter how you try to explain how painful a crisis is, nobody will get it. And I think that has stayed for so, even now, and it needs to change.

SPEAKER 0
[00:33:10,784]When somebody is telling you that I'm in a painful crisis or nobody just wants to leave their house and go and stay in the hospital or be crying or making noise everywhere. When somebody is in the hospital, they must have been there for a reason.

SPEAKER 1
[00:33:26,974]Um, yeah, so that needs to improve.

SPEAKER 0
[00:33:33,214]Yes.

SPEAKER 1
[00:33:34,084]And do you feel that younger people today are getting better care or facing similar challenges?

SPEAKER 1
[00:33:42,754]Because obviously you are in your fifties. I don't know if you have knowledge of anyone who is younger, what has their experience been or what is their experience?

SPEAKER 0
[00:33:53,834]I think um I would say I might be wrong but I would say I think the younger ones they they have they care for them more than the adult because when you go as an adult in people's mind they are like, oh, but it's just a pain you can manage that. But they don't know how painful it is. But with a kid though, oh, it's a child, let me look after a child, but with an adult, they pretend they don't listen to them. They think they are just exaggerating or just looking for attention.

SPEAKER 1
[00:34:25,874]Yes, thank you. Okay. All right, and we're just coming to the final reflection and advice. Um.

SPEAKER 1
[00:34:36,324]What personal strengths or lessons have helped you manage your condition over the years?

SPEAKER 0
[00:34:45,164]Hmm I'll say for example like in my personal life or talking or dealing with the hospital.

SPEAKER 1
[00:34:52,964]No, um, in general.

SPEAKER 0

[00:34:54,604]general

SPEAKER 1
[00:34:55,244]Yeah, it's hospital personnel.

SPEAKER 0
[00:34:57,194]On a personal level, I would say I try as much as possible to know my trigger, what will actually trigger a crisis and try to avoid it. I know for me it's uh cold weather, cold water, stress. I need to rest, take enough sleep. Um, yeah, I try to know my triggers and know what to do and take measures to avoid going through all those things. Okay. And in the hospital, I would say, what I tend to do is, I need to insist, you need to be bold.

SPEAKER 0
[00:35:35,104]you need to fight for yourself because no one is coming there to help you. When you are in pain, no matter how shy they try to stop you from complaining or talking, you need to know what you have to do. For example, if they are not treating you right, you need need to know where you can complain. You need to raise it up. You need to talk about it. Because when you just sit there, because most of the time before, I just you I used to sit and I see other patient they do that. They just cry, oh, I need medication, they are not coming.

SPEAKER 0
[00:36:04,684]they just sit there and cry, but you need to talk, you need to fight. If it means you have to report or race, you have to do it. Nobody will do it for you.

SPEAKER 0
[00:36:13,294]So at first I used to, I used to think, oh, maybe it's just a person because actually you see, I would say racism, because somebody comes to the hospital, you see that they are not even in serious pain, although you cannot judge, but you see from the way they are relaxing, you know that they are not, but you are there crying and crying, everybody is just passing by, not even talking to you.

SPEAKER 0
[00:36:37,324]Not even talking to you or listening to you until you have to scream. I saw one girl the other time, she had to scream five complaints before they came to give her medication. It was above time, they were not giving her. Because she was, you need to learn to talk or look for, you need to to read, to look for, look for all those tools that you can you have to use them.

SPEAKER 1
[00:36:59,364]Have you ever experienced complaint service? Have you ever...

SPEAKER 0
[00:37:04,644]Yes.

SPEAKER 1
[00:37:05,394]with parts

SPEAKER 0
[00:37:06,334]Not with powers, but I don't know.

SPEAKER 1
[00:37:08,854]Do you have a complaint about the service you received?

SPEAKER 0

[00:37:10,784]Yes, I did that in

SPEAKER 0

[00:37:13,364]Um, they came back but they were trying to, it's when I had the PE, the PE, yeah. So they were trying to, oh, we are sorry, or we'll try to investigate and change the process. But on the other hand, you are complaining and on the other hand you are afraid that they might, it might, uh, risk the treatment you will receive. So you are kind of stuck in the middle. Should I complain, should I not? If I complain, what are the repercussions? Will they still treat me the normal way or will they, you know, or will it be, um, what do you call it?

SPEAKER 1

[00:37:50,674]Bye.

SPEAKER 0

[00:37:51,174]Bias, exactly.

SPEAKER 1

[00:37:53,504]That's what's really important. Thank you. Um

SPEAKER 1

[00:37:58,384]My next question is, what do you want healthcare professionals to understand about the reality of living with sickle cell?

SPEAKER 0

[00:38:08,674]I think they should... I don't know how this is possible, but there should be a lot of training within the NHS. They should train people. The fact that, uh, the minority of people have sickle cell like the Africans, uh, Black Africans, Asians, it doesn't mean that they are not supposed to study and know a lot about it. I think there are a lot of people in the UK now with sickle cell patients. Every trust should do a training once in a while, let them know what sickle cell is, especially, um, the Europeans or that they don't know that they don't experience it.

SPEAKER 0

[00:38:44,884]Because I believe that if sickle cell was something that was affecting every race, it would have been different. It would have been different completely, but just the fact that it's affecting the minority is overlooked. They don't actually know the impact of it.

SPEAKER 1

[00:39:00,124]Okay. Thank you. And finally, what advice would you give to someone newly diagnosed or to a single parent managing sickle cell?

SPEAKER 0

[00:39:11,414]I think they should, uh, first of all, try and I know it's still within the community that people don't want, they want to try and hide it or refuse that, oh, it's not what is happening, maybe it's misdiagnosed or things like that. But you have to accept it.

SPEAKER 0

[00:39:26,724]embrace it

SPEAKER 0

[00:39:27,494]look for support groups, talk to people who have gone through, let them advise you and support you on how they have been dealing with it. And I think there should be community groups or charities like the one I'm using. There are some people whose children have not been signed post to any support group. So I think that should be in place. Every community or every

town should have a support group for sickle cell patients.

SPEAKER 1
[00:39:55,114]Thank you so much. Um, um, I know that was Savannah, but I have one more question. Um, we have come across people that are still feeling ashamed.

SPEAKER 0
[00:40:05,394]Yeah.

SPEAKER 1
[00:40:06,084]uh to talk about living with sickle cell and you know, not wanting to access support. What would your advice be to them?

SPEAKER 0
[00:40:16,824]Hmph.

SPEAKER 0
[00:40:18,754]They have to, if you stay quiet in your corner, you won't have the information, the knowledge, the support you need. So staying quiet is not helping you in any way. You have to talk to people, especially if you are an adult, you have to talk to the younger ones because they are struggling, they don't know, but from your experience you will know a thing or two that they don't know. And you have to be bold enough to share that information with them. But people should stop from that uh...

SPEAKER 0
[00:40:48,004]how do you say it from that

SPEAKER 1
[00:40:50,664]Shame.

SPEAKER 0
[00:40:51,394]from that shame Yeah.

SPEAKER 0
[00:40:53,694]that I don't want to talk about. You are keeping it for what? People are out there, you can't see somebody dying and you have information, you have something that can help them and you stay quiet. It's not fair. I will talk about it now because I was once in that situation when I was young. I was looking to see somebody who was older than me with sickle cell to even ask questions. I couldn't find it. So that is the thing that actually triggered, that pushed me to start talking about it. I talk about it now because I know there are younger ones who are struggling. They are not well informed. You go to some sickle cell groups, you hear the things that people are talking and advising others to do.

SPEAKER 0
[00:41:32,724]you just know that they don't know about it. So when you stay quiet, how would that information go out there? you have to talk

SPEAKER 1
[00:41:40,004]Marianne, thank you so much. This was a fantastic interview and we are so grateful.

SPEAKER 0
[00:41:45,464]Thank you. Yeah.

SPEAKER 1
[00:41:46,954]care We're just going to end that. Let's end that. That's over.

SPEAKER 1
[00:41:55,214]Gosh, this is exactly what I needed. I need to... I'd like to...