Antoinette part 1.wav

Interview Summary: Sickle Cell Stories Then and Now

Transcript

SPEAKER_0: Acts as the interviewer for the "Sickle Cell Stories Then and Now" project. Their primary objective is to collect personal narratives from individuals born around 2004 to document the evolution of sickle cell management and patient experiences.

SPEAKER_1 (Antoinette Ali): A 22-year-old participant who provides insights into her life with sickle cell. She discusses the emotional and physical toll of the condition, her history with sports, and her interactions with the NHS.

Key Points And Decisions

Impact of Condition: Antoinette highlights that sickle cell has significantly restricted her ability to participate in sports like basketball and netball, as physical overexertion frequently leads to hospitalizations.

NHS Care: Antoinette expresses a nuanced view of the NHS, acknowledging that she has generally been well-cared for, though she notes specific instances of ignorance among nursing staff.

Daily Reality: A central theme of the discussion is the unpredictability of the condition, which Antoinette describes as "walking on eggshells," emphasizing the constant anxiety regarding potential pain crises or hospital visits.

Project Goal: Both parties agree o]n the importance of the interview in raising awareness about the daily challenges faced by those living with sickle cell, ensuring their experiences are documented and heard.

Next Steps

SPEAKER_0: Will utilize the recorded testimony to contribute to the "Sickle Cell Stories Then and Now" project, ensuring the participant's perspective is integrated into the broader narrative.

SPEAKER_1: No further action items were assigned; the interview session was successfully concluded.

SPEAKER_0
[00:00:04,353]Okay, we start again. Good morning, Antoinette. Um thank you so much for doing this. I really appreciate it. So, this is really simple. We're working on a project called Sickle Cell Stories Then and Now.

SPEAKER_0
[00:00:17,273]And we are collecting stories from real people who have lived with sickle cell so that we can show how things have changed over the years and make sure that people's experiences are heard.

SPEAKER_0
[00:00:29,723]And your story is really special to us because you were born in two thousand and four, the same year the NHS started screening all babies for sickle cell. So you're literally part of the generation, you know.

SPEAKER_0
[00:00:43,163]This was all supposed to help. So this interview really matters to us. And remember, please, there are no right or wrong answers, okay? Just talk to me like you would talk to a friend.

SPEAKER_0
[00:00:54,603]And if there's anything you do not want to answer, just skip it. And you know, this recording is only two minutes long, so uh yeah, just relax. So, can you please just tell me your name and how old you are?

SPEAKER_1
[00:01:09,573]Um my name's Antonette Ali and I'm twenty-two years old.

SPEAKER_0
[00:01:13,943]Okay. So what has it been like growing up with sickle cell your whole life? And do you feel that the NHS has looked after you the way that you deserved?

SPEAKER_1
[00:01:24,883]Um, growing up with sickle cell hasn't been great because um you miss out on a lot of things especially as a child. And the pain is unbearable as well and it's like, you know, it's pretty difficult to deal with.

SPEAKER_1
[00:01:39,473]And in terms of the NHS, I feel like they have looked after me well, but then there had been some You know, some ignorance amongst the nurses, so

SPEAKER_1
[00:01:52,823]Yeah, other than that, I feel like they've looked after me well.

SPEAKER_0
[00:01:56,373]Okay, that's good to know. Has sickle cell ever stopped you from doing something that you really wanted to do and how did that make you feel? Like, can you think?

SPEAKER_1
[00:02:05,723]Yeah. I mean, as a child, I always liked sports. I was into sports like basketball, netball, everything really. And sickle cell stopped me from doing those things because every time I'll do it...

SPEAKER_1
[00:02:19,423]I'd end up in hospital because I did, you know, excess and I'm not like everybody else so I can't, you know, like run across the course like, you know, a thousand times, like it

SPEAKER_1
[00:02:31,103]I end up ending up in hospital so sports has always been like a passion of mine that I wanted to continue doing but Not been able to do because of sickle cell.

SPEAKER_0
[00:02:40,893]So have you stopped doing it?

SPEAKER_1
[00:02:42,683]Yeah, I have to I have stopped doing sports. I do You know, every now and then go to the gym but again it's Things are hard to do.

SPEAKER_0
[00:02:50,833]Okay, would you like to get some help to help manage physical activity?

SPEAKER_1
[00:02:57,013]Yeah.

SPEAKER_0
[00:02:57,733]Oh yeah, because it's really important, isn't it? So, my next question is, what do you wish people understood about what it is actually? Like to live with sickle cell every single day.

SPEAKER_1
[00:03:11,043]I wish that people understood that like it's not easy 'cause you're it feels like you're walking on eggshells. All the time like I might end up in pain tonight or I might end up in the hospital tomorrow.

SPEAKER_1
[00:03:25,353]It's like you always kind of live in life like you know. You living like the fast life trying to like get everything done because you never know when you might end up in hospital next.

SPEAKER_1
[00:03:39,643]So I feel like we uh I wish people understood how hard it really is that we like deal with this condition and It's not really known amongst other people.

SPEAKER_0
[00:03:51,823]Thank you. Thank you very much.