Dr Shola

Sickle Cell Journey and Advocacy: A Discussion with Dr. Olusola Daramola

Speaker Contributions

Speaker 0 (Interviewer): Facilitated the session to document the evolution of sickle cell care over five decades. The interviewer focused on eliciting personal experiences, systemic challenges, and the impact of leadership roles within the sickle cell community.

Speaker 1 (Dr. Olusola Daramola): Provided a detailed account of living with sickle cell disease since childhood. As the Chair of Plasma of Hope and a medical professional, Dr. Chisale contributed insights into the disparities in NHS care, the necessity for cross-specialty medical knowledge, and the importance of patient advocacy.

Key Points and Decisions

Evolution of Care: Both speakers acknowledged that while pain management and the introduction of NICE guidelines have improved care, significant regional disparities persist across the UK.

Systemic Challenges: Dr. Chisale highlighted critical failures in non-hematology specialties, such as ENT and maxillofacial care, where a lack of sickle cell awareness often leads to delayed treatment. The discussion identified that racial bias and the "drug-seeking" stigma remain barriers to effective emergency care.

Clinical Recommendations: There was a consensus on the need for standardized protocols for IV fluid administration during crises and the integration of sickle cell expertise into broader medical specialties.

Resilience and Advocacy: Dr. Chisale emphasized that faith, family support, and proactive self-management are essential for maintaining quality of life, while noting that her lived experience directly informs her leadership at Plasma of Hope.

Next Steps

Dr. Chisale: Continue to leverage her position as Chair of Plasma of Hope to influence national policy and advocate for the implementation of specialized care pathways across all NHS regions.

Project Team: Finalize the "Sickle Cell Stories" project to serve as a resource for policymakers, healthcare providers, and the public, ensuring these experiences inform future care standards.

Advocacy Goal: Promote the inclusion of sickle cell awareness in medical and nursing curricula to ensure that all healthcare professionals are equipped to provide informed, equitable care.

SPEAKER 0
[00:00:02,227]I have got a lot of thoughts, yeah.

SPEAKER 0
[00:00:45,997]Michael may wink.

SPEAKER 0
[00:00:59,037]Okay, let's do it.

SPEAKER 0
[00:01:11,157]Okay.

SPEAKER 0
[00:01:12,757]Dr. Chisale, thank you so much for being here and for agreeing to be part of this project. As chair of Plasma of Hope, you have been a part of this work from the very beginning. But today we are not here to talk about your role in the organization. We're here to hear your story as a person who has lived with sickle cell since 1978.

SPEAKER 0
[00:01:37,387]Wow.

SPEAKER 0
[00:01:39,387]This project is about capturing real experiences from real people so that we can document how sickle cell care has changed over the decades and make sure those experiences are never forgotten. So your perspective spans nearly five decades of life with this condition and that is something nobody else in this project offer.

SPEAKER 1
[00:02:03,237]Indeed, it's good to know it's nearly five decades.

SPEAKER 0
[00:02:07,027]So there are no wrong or right answers. Please speak naturally in your own words. You can pause at any time. We can stop if you need. Take it at your own pace. We can skip any question you do not want to answer.

SPEAKER 0
[00:02:21,737]It's fine. Anything that you're comfortable with, you're in complete control.

SPEAKER 0
[00:02:28,027]So, do we have any questions before we start?

SPEAKER 1
[00:02:31,317]Not exactly.

SPEAKER 0
[00:02:32,497]Okay.

SPEAKER 0
[00:02:34,727]Alright, so this is about your life and the diagnosis section.

SPEAKER 1
[00:02:38,877]Okay.

SPEAKER 0
[00:02:39,527]So, can you tell us about your life growing up with sickle cell disease? What are your earliest memories of understanding what it meant for you?

SPEAKER 1
[00:02:49,847]Well, growing up, my diagnosis was made around seven years of age.

SPEAKER 1
[00:03:01,047]And before then, things were fine, maybe a few neonata issues like neonata jaundice. And then when I was three-year-old, three years old, I realized that I don't like cold. And when I walk in the cold or maybe the bathroom those days used to be at the backyard in Nigeria because I grew up in Nigeria.

SPEAKER 1
[00:03:32,847]The bathroom is at the backyard and when my mom gives me a shower and bringing me in, I sort of feel some niggly pain in my ankle, but it's nothing serious. And usually when the sun is out round about ten, I want to go and stay outside as though there's something that attracts me to the sun because it helps heals the mini crisis.

SPEAKER 1
[00:04:02,587]As it were. And um everything was fine until crisis, real crisis set in at nine, about, yeah, in the mid-nineties when I whilst I was seven or eight. And by then, even though a proper diagnosis was made, was not made then, but my parents knew exactly what was happening because I have an older brother who has the condition.

SPEAKER 1
[00:04:35,607]So I went to the hospital and life started knowing what sickle cell is. And even at then, um having support on the appropriate support of parent because they are educated, they are teachers. I still remembered in my primary four, what we would call year four, I still managed to run 1500 meters. I was a relay racer.

SPEAKER 1
[00:05:07,857]and then I was a relay racer and have got prizes for um athletes.

SPEAKER 1
[00:05:17,367]And until secondary school, um about age ten, um it was I wanted to do things, I wanted to explore. Why not go to Bode Niles? Who tells you I can't go? I've got the brain, I've got the energy, but my parents were not in support. But I always get my way. So I went there to the Bode Niles. Of course, the the care, the TLC I'll get at home was not there, but I went through it anyway. But after three months, I probably came down with...

SPEAKER 1
[00:05:57,907]pneumonia, crises, and boom, I had trouble my first blood transfusion.

SPEAKER 0
[00:06:07,387]Wow, that's amazing to hear. So, I know you mentioned support because your parents were educated, but how did the family respond to the diagnosis? Were they prepared and did they have the support they needed at the time?

SPEAKER 1
[00:06:25,367]Well.

SPEAKER 1

[00:06:27,447]No one prepares for this actually. No one prepares for the diagnosis of sickle cell. But I think I'm I will consider myself lucky because my parents were not negative about it. Even when everyone around felt like, why waste your money? These children will die. They sort of gave me the best.

SPEAKER 1

[00:07:02,727]Um, I remember my mum, those days wedding goats are forever items that they keep. The jewelries, she sold them to buy me medicine. Which was, I mean, at some point I told her not to buy the medicine again because I could see the effort she put in despite financial challenges to make sure that I get my medicine and um all that I needed.

SPEAKER 0

[00:07:38,137]That's so good to hear. Very inspiring.

SPEAKER 0

[00:07:41,227]So, let's talk about the NHS here. With with the NHS care, I mean, what was it like for you in the early years? Did you feel understood, believed, and properly looked after since you got into their care?

SPEAKER 1

[00:07:56,027]Yeah, um, NHS stories have up and downs. You find help sometimes. Sometimes you don't. Sometimes you are not believed. Sometimes you are lucky. I will, because my journey started in Birmingham with the Scotts, Scotts, uh Scotts Treatment Centre, because I was at the time a master's student at the University of Birmingham. For the Scots, I think they understood what sickle cell meant.

SPEAKER 1

[00:08:36,627]And I had my regular clinics and it was okay.

SPEAKER 1

[00:08:45,677]But then sickle cell is not all about hematology because we develop complications outside of hematology. I remember my, um, doctor writing sending me for ophthalmology assessment. And I got there. The ophthalmologist was ranting, like, "What's wrong with her eyes? Why should you have to send her blah blah blah and blah."

SPEAKER 1

[00:09:18,327]but in retrospect, this in the last two years, I went for ophthalmology appointment and the ophthalmologist was like, I had no symptoms even till today. But the ophthalmology now we have to take action. Even though there were no symptoms and they started laser therapy and all of that because there can be complications on the eye.

SPEAKER 1

[00:09:47,337]So, to the first ophthalmologists I met, it didn't see any reason why you as someone with sickle cell should have routine checks of your eye. In actual fact, it should be routine checks of everything in the body, including the kidney, the liver, the liver scans and all that. So that's the story about... um...

SPEAKER 1

[00:10:17,107]Birmingham area And then I moved to Liverpool.

SPEAKER 1

[00:10:23,187]Liverpool the first time I presented, they went like, yeah, you have fever. Yes, I have fever. That's not urgent. That's not emergency. They turned me back at the A&E. And then I

went ahead and say I've got sickle cell.呀呀呀

SPEAKER 1
[00:10:42,037]go and see your GP. I'm like, my fever is not what you should turn down. But of course, I didn't get a voice. And it was turned down. Like, they tried to not send me out of the E and E because my fever is not considered urgent or an emergency. Then I began to have um

SPEAKER 1
[00:11:09,327]I re- in in my first few years in Liverpool it was okay because I am one um person with hemoglobin XSS that would not have frequent crises. For whatever reason I don't know but they think I have some high hemoglobin health that helps me. That's the science behind behind behind it. But once I have crises it can be nasty, like really bad. Those people that have it quite frequently, it's even better for them. But for for those of us that we rarely get it, can be challenging.

SPEAKER 1
[00:11:48,847]I've lived 15 years without it until pregnancy and trouble. Um, I had crisis during pregnancy which was managed adequately.

SPEAKER 1
[00:12:04,147]and

SPEAKER 1
[00:12:05,657]Then there's another complication I developed, which is, um, some avascular necrosis in the jaw, which left some mass that they needed to remove. So, when I go to then then in Liverpool, when I go to, um, dentists, they said, no, no, no, you're meant to see Maxillofacial. I only deal with the tooth, I don't deal with

SPEAKER 1
[00:12:35,727]the maxilla. And when you get to the maxilla, this is actually a complication of the dentist. You go back to the dentist. Then I leave there and the dentist says, oh, if the maxillofacial can't help you, we should refer you to the ENT. Then you get to the ENT. No, no, no. A surgery needs to be done, but it has to be maxillofacial. Ah, for the past four years, even though this is a major setback for my health, I have been rotating between these specialties.

SPEAKER 1
[00:13:14,127]Of course, it comes down to hand gone is not malignant. So, they don't see a reason why it should be treated. But this is not a hematology problem. It is sort of a complication that takes me to other places. Even though if the hematology can actually look after this at me blood wise, but how about other aspects in the NHS? They probably don't understand.

SPEAKER 1
[00:13:53,037]And for many years whilst in Liverpool, it was um it got to a time there was awareness amongst the ANE

SPEAKER 1
[00:14:07,977]And I had a care plan. Once I get there, they may not even wait for a doctor before they start my treatment. So, things are improving but not at a pace we wanted. And then the hematologists in other areas, they are not like Birmingham. So

SPEAKER 1
[00:14:31,977]Most of them are oncologists and you expect them to deal with those. It's challenging.

SPEAKER 1
[00:14:39,657]And then my my work took me to Devon and um that's white dominated. I needed blood and which brings us to the please donate blood our campaign.

SPEAKER 1
[00:14:56,307]anything

SPEAKER 1
[00:14:56,917]needed blood. It was the heat of summer this year, just last month gone. I needed blood and I was like, oh, here, we have to send to Exeter because there's no match. I'm like, oh God. Um, even for a serious business that in the whole lab in my district, not just one hospital, there's no match for me. So they had to go. So I was I was disappointed.

SPEAKER 1
[00:15:33,597]like if this would kill me, then what am I going to do? But luckily, under I don't know how it happened. This blood came from Exeter. It must have been the bloodline, the red line that brought it within one hour thirty minutes, blood was made available for me to take. So with my experience, what I would say is when a child is growing, all they need might just be immunologist and a few specialties.

SPEAKER 1
[00:16:09,537]But when you get to my age, close to five decades, you say, I've never thought of that, but thank you for telling me. Close to five decades. I think getting to your thirties and forties, you need beyond hemathologies. In actual fact, what a hematologist would take you through, you already know after living. But there are complications that are not seen, that are not understood. It might be the first in literature. But other aspects of medicine are not aware.

SPEAKER 1
[00:16:48,207]So, the best I would really advise going forward is that NHS in every specialty ranging from gynaecology to um ENT to medicine, just mention it. There should be what we call gynaecologists with sickle cell interest, special interest in sickle cell. Uh maybe a neurosurgeon.

SPEAKER 1
[00:17:25,837]or in neurologist with special interest in sickle cell. So that in every area, if anybody develops that, or even ophthalmologists, because that's with special interest in sickle cell. I think that's my story. And I know a lot of people in this interview would have said, oh, they don't believe them with anaerobic, blah blah. That's

SPEAKER 1
[00:17:53,007]another one, but I know a lot of people would have mentioned that I won't go there for the day. And again, secondly, another one that comes to play is, um, doctors give analgesic these days. Previously they may not give. But they still downplay that whilst on bed, on admission.

SPEAKER 1
[00:18:18,757]IV fluid is very important. For sickle cell, the blood vessels are blocked. And therefore, when you give the IV fluid, it helps. The NICE guideline is saying give four liters a day. But some people will just give you one liter. Somebody comes, prescribe one liter and goes. Then you you now left to be asking the nurses for more. So they see you as asking for more IV fluid, asking for more analgesics.

SPEAKER 1
[00:18:56,027]And in a way, it triggers people around you to feel that you are a nuisance with

sickle cell on the bed. But then, it's just because even though the doctor knows the guideline, but as a medical doctor myself, I know what happens in the the the the hospital. They are very cautious giving IV fluid for um complications, heart complication, renal complications and so on.

SPEAKER 1
[00:19:29,437]But for us, drinking water, giving IV fluid goes a very long way to help. In actual fact, whilst anesthetic or morphine takes away the pain, the water, the IV fluid takes away the cause of the pain. So there's no point not marrying the two together.

SPEAKER 1
[00:19:55,107]that's what it helped. So a lot of sickle cell are on admission, they don't get enough fluid. I understand some people may be coming from a point of, oh, they may have cardiac complications and all. But I will propose to the NHS, let every sickle cell patient have assessment, heart assessment and fluid regimen recommendation based on that for their admission.

SPEAKER 1
[00:20:32,287]so that when they are horn, they know that they can, this is how much you can push them. And when the doctors come, they should write their entire full fluid for the day. So that in the middle of the night somebody is not unnecessarily in pain and requesting for water and creating nuisance on the ward. I think my experience that's

SPEAKER 1
[00:21:02,657]Yes

SPEAKER 0
[00:21:03,717]which is wow, that's very elaborative.

SPEAKER 0
[00:21:06,727]Yeah. Yes, it covers a lot of the questions that's coming. But um, were there moments when you felt the system has failed you? What happened and how did it make you feel?

SPEAKER 1
[00:21:19,617]Yeah.

SPEAKER 1
[00:21:20,837]it has failed me not directly to NHS on two occasions. I mentioned the jaw mass which I'm still carrying um for some some years now. And what it does is it makes its infected. So frequently I calm down with fever, I calm down with infection. Constantly my inflammatory markers are raised. And if I can in my workplace or for instance,

SPEAKER 1
[00:21:59,107]what I can do, I know I can do better. I can push myself better if everything ties up and I don't have to deal with some sickness that's unnecessary that can be dealt with. That's one.

SPEAKER 1
[00:22:14,427]And again, with um, with gynecology point of view, I've I've suffered from with fibroid since I had my son, that was when it was discovered. So, I would have carried it for nine years before it was treated because it was considered benign.

SPEAKER 1
[00:22:39,147]But then, if in a normal population is considered not a serious thing, but for sickle cell patient should be considered added risk and treated appropriately.

SPEAKER 1
[00:22:59,057]and at the right time. Not like there's no reason why somebody who has anemia should be allowed to bleed excessively for three, four years on the NHS.

SPEAKER 1
[00:23:13,037]So, it's like when when triage is done for who should be get emergency treatment, which treatment should be prioritized. The sickle cell part of the is downplayed. Whilst well-known conditions, maybe even diabetes, is prioritized. Sickle cell does not ring a bell to many of the people that does triage. And yeah.

SPEAKER 0
[00:23:49,397]Thank you.

SPEAKER 0
[00:23:51,407]Okay, so we're moving on to the care then and now. You have lived through nearly five decades like we've mentioned of NHS sickle cell care. What stands out most when you compare where things were to where things are now?

SPEAKER 1
[00:24:08,187]Yeah. I would say my my childhood was in Nigeria. I came into the UK in 2008. And luckily for me, I wasn't

SPEAKER 1
[00:24:21,357]Birmingham. And I feel I got the appropriate treatment. But shortly after that, my job had taken me to many places. And when you're a black person, you knock at the door for Christ's sake, those days outside of Birmingham, I would say. And you ask for an agentic.

SPEAKER 1
[00:24:49,137]it's a challenge because they see you as drug-seeking, morphine-seeking, and so on and so forth. Personally, I react to morphine, but I still need it when I need it. So I don't take it a lot. So, but then it's it's a challenge and the awareness whilst they are very good in places like London. I had a I I I had the worst sickness of my life sometimes since 2024.

SPEAKER 1
[00:25:28,327]And the treatment they gave me in London, I wouldn't get it elsewhere.

SPEAKER 1
[00:25:34,527]the Medway Hospital near Kent. It was from the A&E to hematology ward, I did not fault their management. these days

SPEAKER 1
[00:25:49,787]and that's it, that is where we want to be. And I wish such protocols, such awareness can happen elsewhere in the country. So, um somebody who has traveled the UK wide, I've worked in Scotland, worked in Wales, worked in southwest, southeast, north northeast, northwest, just mention it. So, I have a picture of

SPEAKER 1
[00:26:16,037]divisions and I know the awareness and the treatment we get there. So, if I would rate the the the treatment I got in London, five stars.

SPEAKER 0
[00:26:30,317]Oh

SPEAKER 1
[00:26:31,147]I mean, other places still needs to get there. So we're not at the same level in the country.

SPEAKER 0
[00:26:40,077]Okay Alright. So what do you think were the most significant turning points in how sickle cell care has evolved in the UK during your lifetime?

SPEAKER 1
[00:26:52,627]Come again, please.

SPEAKER 0
[00:26:54,687]So we've made to like significant turning points in your journey, how it has evolved.

SPEAKER 1
[00:27:03,827]Yeah.

SPEAKER 0
[00:27:04,817]yeah, like you were comparing the regions and all that.

SPEAKER 1
[00:27:08,447]So, earlier on, maybe eighteen years ago, I think not a lot of people knew about sickle cell. And but then over the years, a lot of management strategies has come up. Um we now have nice guidelines that recognizes the treatment pathway for crisis, only crisis.

SPEAKER 1
[00:27:39,957]their order

SPEAKER 1
[00:27:41,217]complications of sickle cell that would still need nice guidelines to take hope, um particularly in other specialties. So, we are lucky to have nice guidelines and um there's been report that's airports like they are not listening and experiences of people that were published as help things move further. But I would say we're not where we should be in all the parts of the country.

SPEAKER 1
[00:28:15,817]and um I remember then in 2008, I wasn't offered hydroxyurea because yes, because they felt the guideline, um I've not had three consecutive crises in one year.

SPEAKER 1
[00:28:32,777]they they they say

SPEAKER 1
[00:28:34,187]criteria you have to fulfill. But I think these days, hydroxyurea is offered at will when if to every, I believe to every adult with sickle cell now have the access to hydroxyurea. Thus, and over the years, there's been many drug trials, there are more researches looking after sickle cell and um

SPEAKER 1
[00:29:02,187]and people get some donated gets frequent transfusion and going forward, um, I think there are more awareness, there are more awareness about bone marrow transplant, the gas gave hand, so and the the gene therapy.

SPEAKER 1
[00:29:26,867]which we we understand that fifteen maybe twenty-five people in a year, but I have not seen one who has had the the gene therapy in the UK.

SPEAKER 0
[00:29:42,947]Right. So pain management has been one of the most persistent failures in sickle cell care. What has your experience of that been across the years?

SPEAKER 1
[00:29:55,327]Yeah. I think pain management is a little bit better than before.

SPEAKER 1
[00:30:05,037]Now, I mean from the it might be different in other places but from places I've been to, they understand that opioid or morphine is necessary. And I think the addiction perspective

SPEAKER 1
[00:30:27,157]is reduced and yet in pain management, I think it's better from an anesthetic point of view. But going from there, I think there's still a lot of work to do about the awareness of IV fluid rehydration whilst they are on the hospital because the the nurses often argue that they can drink water.

SPEAKER 1
[00:31:00,067]but if you ever experienced the pain of sickle cell, you know how it is even difficult to sip water. And somebody who's had pain all day at night, they there's no way they can be drinking water. And that's when they don't get water and IV fluid because the doctors are not... the presence of the doctor are not as much on the ward as it was in the morning.

SPEAKER 1
[00:31:33,877]so it means that they do really need to more awareness on IV fluid.

SPEAKER 0
[00:31:43,197]Такие вот So I remember you mentioned the lack of um Blood match for you because of the AUE. Yeah.

SPEAKER 0
[00:31:53,787]So has racial bias played a role in how you've been treated by the NHS? How has that changed or not changed over the decades?

SPEAKER 1
[00:32:06,207]Um, I think it has played a role and it depends on where you're coming from.

SPEAKER 1
[00:32:20,797]I think is still very much present, unfortunately.

SPEAKER 1
[00:32:27,717]Um, for instance, I I personally wrote a letter to Pals on how I was treated. Because two doctors turned at my bed and they said they know me and um one of them said she she knows me. I only know one of them and the other one said she knows me and my question was how?

SPEAKER 1
[00:32:56,697]where

SPEAKER 1
[00:32:57,687]you will never, you've never attended to me. You've never um seen me in a clinic and you know me. But I have a feeling one of them actually briefed her and she said, yes, but then um they need the bed. And now I have to get out.

SPEAKER 1
[00:33:19,147]Yes.

SPEAKER 1
[00:33:20,297]So I was pushed out of the hospital at 10 p.m. At the risk of always speaking me and so on, they said maybe I go to the corridor and stay there. They need my bed because there are more urgent cases to attend to.

SPEAKER 1
[00:33:40,237]10 PM, I was flung out of the hospital. And I know that is racially or stigma kind of mastermind because one would have informed the other about me and they just adamant. I wrote to pass about it, but I I suspect maybe they wrote back or they didn't. I'm not sure, but the email I used then before I relocated, I I don't have access to it anymore, so.

SPEAKER 0
[00:34:17,677]Yeah.

SPEAKER 1
[00:34:18,967]So I think there's still a lot of racial racial background to the care of sickle cell. Definitely.

SPEAKER 0
[00:34:30,367]It's sad to hear. Okay, we're moving on to liver with sickle cell.

SPEAKER 0
[00:34:37,987]How has sickle cell shaped your life, your choices, your relationships, and your sense of who you are today?

SPEAKER 1
[00:34:46,557]Okay, let's take it one by one.

SPEAKER 0
[00:34:49,307]The first one is, uh, sickle cell shaped your life.

SPEAKER 1
[00:34:54,337]Well, I'm thankful for how God made me because as a child I felt like, oh, come on. This this sickle cell candy, somebody should just give me a draw candies.

SPEAKER 1
[00:35:13,507]And he takes it away. And I felt all the doctors around me are just dumb-headed.

SPEAKER 1
[00:35:20,657]Unfortunately. And I thought, okay, when I read study my own medicine, then I will I'm going to tell all of them that they don't know as much as I do. That was what brought me to study medicine.

SPEAKER 1
[00:35:38,497]And um I'm working as a doctor today. I've contributed to the field of hematology,

but I think I'm still like every other doctor anyway that does not know the cure to sickle cell that's shaping my career, shaping my life. Yeah, I think I would have, yeah, there's a lot of things that I would love to achieve. Maybe I achieve them, but not at the right time.

SPEAKER 1

[00:36:10,977]maybe could be take longer, could take could be slower, but not extremely slow, but I put so much energy into everything I do to get to where I am. And maybe I would be a billionaire or something like if I don't have sickle cell.

SPEAKER 1

[00:36:35,697]but then I'm very thankful for life. And um a lot of things when it comes to energy, sometimes it's there completely, but other times it's not there. And sometimes they I don't let titling along, but sometimes the the the the the mental effects could make you think one of two things.

SPEAKER 1

[00:37:12,827]but I sort of like helped myself a lot to get out of it and not allow it to weigh me down. And then when it comes to relationship, of course, um while I was younger having relationship, I was the upping babe, you know. But then I had a lot of relationship, I can't count them really. But I think, of course, they may not tell you one on one that is because of your secret self things will not work out. But it didn't work out.

SPEAKER 1

[00:37:52,887]and there are ones that you have to be specific if you want to marry somebody who who's got the A H genotype so that you can have children. There's a lot of complications which we can't continue to mention in this interview, but it's it's very challenging for everyone living with sickle cell.

SPEAKER 0

[00:38:16,217]Thank you for that. So, what has been the hardest period of your life in relation to sickle cell and what got you through it?

SPEAKER 1

[00:38:27,237]Well, I think the, I wouldn't say hard, I guess, but the most annoying thing is just because right now I, I have a treatment that is lingering and it's not been, I've not seen a solution to it. I'm still just going one place to the other. I have a schedule, another surgery scheduled, and somehow it's cancelled, another one comes up.

SPEAKER 1

[00:38:57,407]But I just want to adhere to it really, so that I can live my life normally without worrying about another fever is going to set in because of one complication that can be dealt with in 30 minutes really. And I'm taking it, it's very annoying.

SPEAKER 0

[00:39:18,867]Are you coping through every day?

SPEAKER 1

[00:39:22,807]A lot of people ask me that question, but

SPEAKER 1

[00:39:28,147]I seem not to know how to answer it because it's it's still a challenge for myself. I can't explain how I'm coping. As you know, I have a 10-year-old boy to look after. And sometimes when I'm when I'm doing school runs on my way back from school, I'm just feeling sleepy. I just

parked nearest Tesco or Sainsbury's.

SPEAKER 1
[00:39:58,267]I just take a nap. And my son knows to keep shut at that time. And the way, you know, it's just because I'm tired and I can't carry on. I just take a break, park, take a nap. And then I always instruct my son in such instances. It doesn't take that, that nap doesn't take me 30 minutes. It could be five minutes, it could be 10 minutes, and I'm refreshed. And I continue.

SPEAKER 1
[00:40:27,157]So, coping with childcare and I basically arranged my life such that where I go, it goes.

SPEAKER 0
[00:40:38,297]Mmm-hmm.

SPEAKER 1
[00:40:39,257]except for new studio. And if I can't find cover for him, I just don't do those things. That's I I sort of prioritize my yeah, my my my my activities and make sure that my health is looked after. I prioritize the need of my child. And also, I make sure that my health does not impact my work in any way.

SPEAKER 0
[00:41:13,147]excuse talking about childcare arrangement and all, what role has faith, family, community or prayer posts played in sustaining you through the difficult years?

SPEAKER 1
[00:41:27,087]Yes.

SPEAKER 1
[00:41:28,107]Family had done a lot because my mom was able to come over in the early days while I was young. She was practically living in the UK, probably a visa of six months. It expired, she goes back and comes back again on visiting visa. So she helped a lot with um school runs, childcare in the early days.

SPEAKER 1
[00:41:58,207]and faith. Faith is one thing that helps me with with the positive aspect of things because faith helps me to think positively rather than seeing things that is doom and I can't make it go from here now. Faith helps me to be positive about life.

SPEAKER 0
[00:42:26,067]Yeah. It's good to hear. Now, what have you had to give up because of sickle cell disease and what have you absolutely refused to give up?

SPEAKER 1
[00:42:38,787]as challenged

SPEAKER 1
[00:42:44,107]web

SPEAKER 1
[00:42:45,587]I think in my career, I wanted to be a hematologist really. But I realized that the route is going to be very challenging because there'll be nights, nighttime calls and all that. I realize, hmm, it might not be the best for me. And um...

SPEAKER 1
[00:43:15,167]I I gave up that because that was what really brought me to my part of Korea. And what I did not give up is is um my relevance in the medical field. Even though being an hematologist from the clinical perspective is not possible, I decided to be a hematopathologist from the laboratory side of things.

SPEAKER 0
[00:43:53,437]It's still the way.

SPEAKER 1
[00:43:54,877]Yes. It's still a win-win.

SPEAKER 0
[00:43:57,447]Okay Thank you for that. We're going to move on to your role at Plasmo now.

SPEAKER 0
[00:44:03,827]Yeah, so what drew you to becoming the chair of Plasma of Hope? And how does your own lived experience of sickle cell inform the way you lead?

SPEAKER 1
[00:44:14,567]Yes, thank you very much for that. That's a valid question.

SPEAKER 1
[00:44:21,127]Um, my... from very young age, I have wanted a solution to sickle cell. And when I know someone has sickle cell, I want to do everything in my power to encourage that person just to say, "My life is here and I'm living life and I'm making it, you can." So I want to help, I want to encourage someone with sickle cell.

SPEAKER 1
[00:44:57,617]and most importantly, I want to meet their needs in the best possible way I can. And um the opportunity to lead as a chair in Placemouth came and I embraced it wholeheartedly. And living with sickle cell informs my leadership because I see the pain of people around.

SPEAKER 1
[00:45:29,317]I know having firsthand of their of their need and I'm able to share my experience

SPEAKER 1
[00:45:43,077]use it as a platform to teach, to encourage people living with sickle cell and how to manage themselves.

SPEAKER 0
[00:45:57,237]Okay So what do you hope Plasma for Hope will achieve for the sickle cell community that has not yet been achieved?

SPEAKER 1
[00:46:05,547]Yes.

SPEAKER 1
[00:46:07,067]Plasma of Hope has done a lot for us in the Midlands, but I want a greater voice for Plasma of Hope whereby whilst we cannot be present everywhere in the country, but I think policies should be influenced by Plasma of Hope. Uh, in regards to everything I've been saying about how we can be looked after in a better way.

SPEAKER 0
[00:46:44,727]perfectly So what does it mean to you personally to be the part of this project, the Sickle Cell Stories then and now?

SPEAKER 1
[00:46:56,167]Yes, it's because uh...

SPEAKER 1
[00:47:02,267]you like you previously said, I've lived for a while with sickle cell, going to five decades, and I've seen it evolve.

SPEAKER 1
[00:47:14,867]I believe it is story that would also influence the next generation. These are stories that generation will see and learn for from.

SPEAKER 1
[00:47:31,977]and these are stories, stories that will inform the the the the the management of sickle cell. These are stories others living with sickle cell will see and have. So it's endless.

SPEAKER 0
[00:47:52,757]Oui Thank you so much so far. In the end, we can look forward into the future. I know you've mentioned gene therapy.

SPEAKER 0
[00:48:04,347]Yes, so gene therapy for sickle cell disease has now been approved. What does that mean to you after nearly five decades of living with the condition?

SPEAKER 1
[00:48:14,667]I'm excited about it. particularly for the generation coming

SPEAKER 1
[00:48:22,527]because the things we believe through, the things, the pain we went through, it looks like it's going to be more affordable at some point.

SPEAKER 1
[00:48:37,537]the costs might be high now, but I believe in the next gen, not now, people living with sickle cell will get better care. And they will even get better solution beyond gene therapy. And it's it's it's just, it's just given that the world is doing a lot in the area of sickle cell and it will transform lives of people.

SPEAKER 0
[00:49:15,067]Okay Thank you. So what do you want the NHS policymakers and the wider public to take from this project and from your story specifically?

SPEAKER 1
[00:49:27,257]Indeed.

SPEAKER 1
[00:49:28,527]Everything I've said. I think the awareness should be um start from all our caregivers. Maybe something that should be included in their curriculum from nursing school, physiotherapy, medical school, maybe

SPEAKER 1
[00:49:54,451]A cecosel should form a part of their curriculum so that when they become professionals, they don't struggle with understanding what cecosel is.

SPEAKER 1
[00:50:09,431]And also to the policy makers to see the challenges from this story, the, the, the, the, the challenges people living with sickle cell are going through. And I, I remember, um, in NHS, there's certain, um, compulsory learnings, e.g., Oliver Goan.

SPEAKER 1
[00:50:40,521]And so, these are, this came, um, this particular Oliver Goan, um, series came as a result of experience of a mother living with, um, uh, with, um, of a mother of a child living with disability. And it is compulsory. Even if not every NHS staff must do this. I, as someone who works in an NHS, I believe such webinars could be, could come up in relation to sickle cell.

SPEAKER 1
[00:51:20,811]Just for, not just for caregivers or staff because some of us are joining the workforce so that the workforce will understand us. The caregivers will understand us. So I, I, I look forward to such a compulsory learning at this stage and I want the, the, the policymaker to look into, um, um,

SPEAKER 1
[00:51:49,091]designing a good protocol or a workable protocol for IV fluid administration for patients on, um, with crisis, on crisis. And I also want them to go into other, other fields of medicine to have people with special interest in sickle cell.

SPEAKER 0
[00:52:14,621]Okay. Now, just before, What gives you the most hope when you think about the future of sickle cell care in the UK?

SPEAKER 1
[00:52:27,611]Most hope?

SPEAKER 1
[00:52:30,011]I still, there has been improvement, but I think there's still a lot of work to do. And, yes, I have hope in that places like London, they are where they should be.

SPEAKER 1
[00:52:53,811]And I believe in the care we get from Scots and Birmingham area.

SPEAKER 1
[00:53:02,231]I think if that level of understanding and care for sickle cell can be replicated in other parts of the country, then we go a long way. I think, yeah, I'm hopeful that, yes, if I want to retire, I go to London, I can rest, and there'll be hands to look after me in Medway Hospital, Kent.

SPEAKER 0
[00:53:27,361]Okay. Right, last but not the least, what message would you give to someone who has just been diagnosed with sickle cell disease today?

SPEAKER 1
[00:53:37,401]I think I have a message for every person. Who has been diagnosed with sickle cell and their carers. I think it's a challenging journey.

SPEAKER 1
[00:53:51,491]But it's never a death sentence. People are living life and happily living life with sickle cell. Um, it's very important to have

SPEAKER 1
[00:54:10,141]Positive energy for parents not to see children as burdens because they have sickle cell because it does impact mental health and that is where, that is the, I believe that is one thing that increases the mortality of sickle cell when the mental health is deranged, when There's so much negative energy, such as stigma, such as parents seeing them as bad things, such as them seeing them as draining their finances.

SPEAKER 1
[00:54:49,011]I think whatever you need for carers who have someone living with sickle cell, just make sure you give them back that positive energy around them. Um, go to clinics as expected.

SPEAKER 1
[00:55:07,141]Um, ask questions from your hematologists, from your clinicians, and if you feel something is wrong, please don't stop. Even if they don't listen, make them listen until they listen, and listen, and listen over and over again.

SPEAKER 0
[00:55:27,021]Well, thank you so much, Neta Shala. Your story, your leadership, and your courage in sharing both. I give to this project and everyone who will read the booklet. We're so grateful that he spent the time to do this.

SPEAKER 1
[00:55:41,911]Thank you.

SPEAKER 0
[00:55:42,411]Thank you so much.

SPEAKER 1
[00:55:43,651]Thank you. Thank you.