Tamara Mc.wav

Sickle Cell Stories: A Personal Journey and Advocacy

Summary Of Each Speaker

Geraldine (Speaker 0): Acting as the project lead for "Sickle Cell Stories, Then and Now," supported by the National Lottery Heritage Fund, Geraldine facilitates the interview. Her primary contribution is creating a supportive, non-pressured environment to document the lived experiences of individuals with sickle cell disease to drive future awareness and systemic change.

Tamara (Speaker 1): A participant living with sickle cell disease for 46 years. She provides a detailed account of her medical journey, including multiple hip surgeries, severe complications from blood transfusion allergies, and respiratory issues. She contributes insights into the psychological and physical toll of the condition, the loss of independence, and the challenges of navigating the healthcare system.

Key Points And Decisions

Medical Challenges: Tamara details a history of complex surgeries and severe reactions to standard treatments, such as blood transfusions, which have led to long-term nerve damage and reliance on 24-hour oxygen.

Systemic Frustrations: A significant point of disagreement exists between the patient's needs and the current NHS support. Tamara highlights a lack of empathy from medical staff, long wait times in A&E, and the denial of necessary mobility equipment, such as a reclining chair, despite her physical limitations.

Impact on Daily Life: The conversation establishes that sickle cell is highly unpredictable. Tamara emphasizes that her "good days" are often misinterpreted by professionals as a lack of need for support, which complicates her access to care and housing.

Resilience and Advocacy: Both speakers agree on the importance of sharing these stories. Tamara decides to participate despite her physical pain, viewing her testimony as a necessary act to help others understand the reality of the condition.

Next Steps

Geraldine: Will continue to compile the collected narratives for the "Sickle Cell Stories, Then and Now" project to ensure the experiences shared are used to advocate for better patient care and public understanding.

Tamara: Will continue to manage her health on a day-to-day basis, focusing on maintaining mental well-being and independence where possible, while providing her story as a resource for the project's broader goals.

SPEAKER_0
[00:00:03,763]Okay, so thank you so much for agreeing to speak with us today. My name is Geraldine, like I said before. And I'm here on behalf of Plasma and our project for Sickle Cell Stories, Then and Now, which is supported by the National Lottery Heritage Fund. Yeah. Okay, so I want to start by saying how much this means to us that you are here. Yeah. I know it's not easy for you to drive all the way down. And I know today is not an easy day, but I want you to know that there is absolutely no pressure. We said before. And this is entirely on your terms.

SPEAKER_0
[00:00:40,463]Yeah, we're collecting real stories from real people who have lived with sickle cell disease so that the world can understand what it truly means to live with a condition like that and so that brings changes to people who come after you. So it's important to share our stories. Mhm. Yeah. You know, the story is one of the most important in the project. You have lived through things that most people will never understand. And you have agreed to share that with us. This is an act of real courage and generosity. So we are grateful that you joined us today.

SPEAKER_0
[00:01:16,463]Thank you so much.

SPEAKER_0
[00:01:24,113]We're gonna have a gentle conversation.

SPEAKER_0
[00:01:27,923]you're not being interviewed for a position or role, so it's not rigorous, it's no wrong answers. Just yeah, if at any point at all like you want to stop, let me know you want to stop. You want to take a break, you want to skip, if there's any answer you don't want to answer, just say it, yeah. Okay. There's no rush and nothing you have to do, we're simply here to listen. If you're uncomfortable, if there's anything you need before we begin, you let me know.

SPEAKER_1
[00:01:58,383]That's alright.

SPEAKER_0
[00:01:59,883]Okay.

SPEAKER_0
[00:02:02,583]All right, so we can get straight on. So you have lived with sickle cell for over forty-five years.

SPEAKER_1
[00:02:12,893]six years

SPEAKER_0
[00:02:14,343]Forty-six. I'll change that.

SPEAKER_0
[00:02:18,963]And it's taken a serious toll on your body as I can see. Yeah. In your own words, what has the journey been like and what do you most want people to understand about what your life has truly been?

SPEAKER_1
[00:02:34,223]The sickness has really changed my life because I was okay most of the time when I was nineteen. I got sick at nineteen twenty.

SPEAKER_1
[00:02:47,193]I mean, yeah. then it started to affect the bone, my hips. age 21

SPEAKER_1
[00:02:58,353]I was in Jamaica at the time. I was living in Jamaica. Yes

SPEAKER_1
[00:03:04,333]Then I came over here 'cause when I was in Jamaica they said they couldn't do a surgery then because I was still young.

SPEAKER_1
[00:03:15,103]So I'd have to wait until I am 25 in Jamaica. But then I came here at the age of 22. Still having back pain, I went to the doctors and they said they have to do it now.

SPEAKER_1
[00:03:29,743]So when they do it now, if I don't do it now, I won't be able to walk again. That's what it says. So, I ended up doing it.

SPEAKER_1
[00:03:41,683]two thousand

SPEAKER_1
[00:03:44,133]2002, my first surgery, yes. Yes.

SPEAKER_1
[00:03:49,553]one before six months apart and then I was working again and then I felt something sticking in my hip again. They said the screw was loose so I got to go back again and do an X-ray again to warm it up and fix that screw again. And it's supposed to last for fifteen years, ten years to fifteen years, but it ends up lasting for like twenty years.

SPEAKER_1
[00:04:25,363]And so I was working, I was a support worker.

SPEAKER_1
[00:04:32,963]support work I was a support worker, yes. Then my hip started to affect me again. Twenty twenty-three.

SPEAKER_1
[00:04:42,643]And then I've done, I've done the surgery 2023. I'm allergic to blood transfusion. Because some sickle cells can get blood, but I'm allergic to blood transfusion. So...

SPEAKER_0
[00:04:54,403]Means you can't take any blame.

SPEAKER_1
[00:04:56,763]and now 'Cause most sickle cell people get blood transfusions.

SPEAKER_0
[00:05:00,113]on blood transfusion

SPEAKER_1
[00:05:01,393]Well, I'm allergic to blood transfusions, so that's where the problem is, so

SPEAKER_1
[00:05:08,563]أبدى السعد أبدا

SPEAKER_1
[00:05:11,433]my surgery again in 2023 because I was supposed to be off work for three months as they say. But as it turns around, I'm off work for three years and they write me off for simple B because I've done the surgery. They gave me a blood transfusion and I was in intensive care for a whole month.

SPEAKER_1
[00:05:39,433]My liver and my kidney were failing then. My heart was failing then.

SPEAKER_1
[00:05:47,313]So, I've got nerve damage in my leg as well. I've got a limp leg as well. The left falls dead, cannot move.

SPEAKER_1
[00:05:59,513]uh, of course, so, when I've done that surgery, it didn't go properly.

SPEAKER_1
[00:06:08,993]the joint slipped back out again and they fixed it, they sent me home. And when I was home for two weeks, it slipped back out again and I got to go back in again and do the next surgery. And I was like that for like one year straight.

SPEAKER_0
[00:06:32,883]Wow.

SPEAKER_1
[00:06:33,803]So other nerves get damaged.

SPEAKER_1
[00:06:39,953]and my lungs are not functioning well because there are clots in my lungs. So now, I'm living on blood thinners.

SPEAKER_0
[00:06:53,913]Yes

SPEAKER_1
[00:06:55,183]my liver got damaged, there's not a big thing though.

SPEAKER_0
[00:06:58,663]They can't know.

SPEAKER_1
[00:07:00,383]so, that leaves me with so many complications now, so basically I can't work. Aka akwụnụ n'okpuru

SPEAKER_1
[00:07:11,523]So this is my life now. It wasn't like a bit of depression because I could have come to terms with my life just changed like that. So, it really gets me down, but my therapy, my therapy is driving.

SPEAKER_0
[00:07:32,393]Yeah

SPEAKER_1
[00:07:33,213]When I drive, my brain doesn't really think about that stuff. Basically, that's it.

SPEAKER_0
[00:07:42,763]Das ist das Herz.

SPEAKER_1
[00:07:45,483]Yeah, I can't do anything on my own 'cause if I'm going shopping, I've got to go with my sister 'cause I cannot manage shopping anymore. My sister's going to do my shopping. My brother's going to do my shopping.

SPEAKER_1
[00:07:57,263]I can't bend to put my socks on because of my hips. So this, I've got carers that come in.

SPEAKER_0
[00:08:05,893]Oh, dear God.

SPEAKER_1
[00:08:06,943]and help me seven days a week, so yeah.

SPEAKER_0
[00:08:12,663]Um, that's a lot for one person.

SPEAKER_1
[00:08:16,043]Yeah.

SPEAKER_0
[00:08:16,683]There's a lot of things. Yeah, yeah. Yeah. So, despite everything you're going through right now, you still choose to be here and share your story?

SPEAKER_1
[00:08:27,383]Yeah

SPEAKER_0
[00:08:27,963]Why does it matter for you to share the story? I don't know.

SPEAKER_1
[00:08:31,133]I don't think they understand what it is like for your life to just change.

SPEAKER_1
[00:08:38,703]I'm handicapped for three years trying to get a bungalow, trying to get a suitable property because of my hips going up and down the stairs.

SPEAKER_1
[00:08:51,263]Não, não, nada. Um um um on parties on the council and there 's nothing there.

SPEAKER_1
[00:09:01,103]Because of the oxygen, I'm not supposed to be around people who smoke.

SPEAKER_1
[00:09:06,183]So, putting me in an air rising building with smokers and it's not because I've got oxygen in the night, a big thing that they do.

SPEAKER_0
[00:09:20,143]Just

SPEAKER_0
[00:09:23,843]Да, это не наш список. Okay, so

SPEAKER_0
[00:09:29,153]We're going to move on a little bit to early memories of sickle cell. What was your earliest memory of living with sickle cell disease? How old were you when you truly understood what it meant for your life?

SPEAKER_1
[00:09:46,543]Wow.

SPEAKER_1
[00:09:48,063]going to primary school, uh, I noticed that I was sickly. I'm in school this week and I'm off of school next week. And I'm in school the other month. So I missed a lot of my schooling, but I still go to school but some days, some weeks, I can't go 'cause I'm in the hospital or whatever. But try to avoid it. No. I've got my cousins and everything, so it wasn't that bad.

SPEAKER_1
[00:10:24,123]It wasn't that bad until I came to this country, I don't have support. It's really hard.

SPEAKER_1
[00:10:31,803]And if you just come to this country and you're doing immigration stuff and so forth and nobody can help you and you're not entitled to stuff, it's really bad.

SPEAKER_0
[00:10:43,983]Yeah, that must be very difficult. Yeah. And then talking of that, what was the NHS care supportive?

SPEAKER_1
[00:10:53,723]What was it like in the early years?

SPEAKER_0
[00:10:56,383]Did you feel understood properly?

SPEAKER_1
[00:10:59,823]No, I don't understand properly but NHS people... when I go into hospital, uh um, her sister's a nurse. So...

SPEAKER_1
[00:11:16,983]I think it wasn't that bad for me because when she comes in, she can see my notes and know what's going on. But for me, she checks with them so she knows what's going on, but if she wasn't there, then it would be a different story 'cause the nurses are on the wards, they just do whatever they feel like doing, so yeah.

SPEAKER_0
[00:11:42,823]So that was the only part of the NHS. So have there been times when you felt your

pain was not taken seriously or you were not believed for what you were saying? Can you tell us a bit of what happened?

SPEAKER_1
[00:11:57,503]No, no, no.

SPEAKER_0
[00:11:58,873]they always believed you and they listened. Okay, that's good to hear.

SPEAKER_1
[00:12:05,533]because of narcissism and also, I never go to hospital on my own.

SPEAKER_0
[00:12:11,663]Okay, so she was always there.

SPEAKER_1
[00:12:13,413]situations

SPEAKER_0
[00:12:14,753]Oh, that's good to know. So, how has sickle cell shaped your life, your relationships, and the things you have been able to do so far?

SPEAKER_1
[00:12:25,073]Mmm, it's alright. 'Cause once you have a, once you have a husband or a boyfriend, whatever you call it, if they don't understand that's the way it works, it's not for yourself.

SPEAKER_1
[00:12:40,563]E se você usar Yeah.

SPEAKER_0
[00:12:44,163]But you have good relationship with

SPEAKER_1
[00:12:47,763]a good relationship with everyone, everybody who is around me understands.

SPEAKER_0
[00:12:53,133]understand the conditions

SPEAKER_1
[00:12:54,703]even when I'm feeling sick, I'm feeling sick and when I'm not feeling sick, I'm not feeling sick. When I'm feeling sick, people like... like, I don't want to call names but people like therapists and those, they don't understand how sick I self work because today I can be okay.

SPEAKER_0
[00:13:18,853]Yeah.

SPEAKER_1
[00:13:19,883]This week I'm okay. Next, this month I'm okay. And then you don't know what happened.

SPEAKER_0
[00:13:28,133]next

SPEAKER_1
[00:13:29,423]And the next day you're just not okay. So that's how it works. Yes, so they have been the same um you can move around now so you don't need this chair. But there's come when I can't move around and I do need that chair. So

SPEAKER_1
[00:13:48,283]These are the challenges they go through with sickle cell that they think it's okay now because they see you're okay, but at the next minute, you do need it. Okay, tomorrow.

SPEAKER_1
[00:14:02,083]You can move around now, you don't need that chair, but when you leave me now in less than a minute.

SPEAKER_1
[00:14:13,153]I fell down but I don't need a chair. Because you see me half and bubbly today doesn't mean that I'm going to be bubbly every day. Every day could... that's how the system works.

SPEAKER_0
[00:14:28,253]Okay.

SPEAKER_1
[00:14:29,913]And the job needs to understand when you go to work, they don't, they don't, they think they think you may be lying.

SPEAKER_0
[00:14:38,873]you make me laugh

SPEAKER_1
[00:14:39,773]are so you have to bring a doctor's note and doctor's test because they think you're telling a lie, but today I'm okay, tomorrow I'm not. So that's the way it's, that's the way it's supposed to work.

SPEAKER_0
[00:14:53,613]Okay. Yeah, you know it can be very unpredictable. That's a theme that runs through everybody we've spoken to, isn't it? You can't tell when they're going to be okay.

SPEAKER_1
[00:15:05,743]music, yeah. Yeah. It's just... It just comes on. It just it just it just it just comes on.

SPEAKER_0
[00:15:10,593]Yeah. Okay.

SPEAKER_0
[00:15:12,623]Shall we shift a little bit to the complications you had earlier on and then your care? You've had multiple hip operations over the years. What has that experience been like and how has it affected your day-to-day life?

SPEAKER_1
[00:15:27,323]My day to day life, as I said, because of the last surgery that I did. And they had to go in so many times, they gave me blood.

SPEAKER_1

[00:15:40,963]faints and blood. And that's the killer that's linked my body in because I'm allergic to blood transfusion.

SPEAKER_1
[00:15:50,303]And they said they have to give it to me because I've lost a lot of blood, but when I did my surgery for the first time in April, my hair came back.

SPEAKER_0
[00:16:07,053]Ja, komm, ich hab Zeit.

SPEAKER_1
[00:16:12,173]Hello.

SPEAKER_1
[00:16:16,773]Everything Meu fã

SPEAKER_1
[00:16:32,593]Who's coming?

SPEAKER_1
[00:16:40,373]And, who would be on the call?

SPEAKER_1
[00:16:44,943]No.

SPEAKER_1
[00:16:48,863]What's more?

SPEAKER_1
[00:16:53,503]Okay.

SPEAKER_0
[00:16:56,363]Okay, so, would you want to finish that before you...

SPEAKER_1
[00:17:02,923]I can carry on. Yeah.

SPEAKER_0
[00:17:05,223]Yeah. So you elaborated on how it affects your day-to-day life?

SPEAKER_1
[00:17:15,833]They just limit me from doing stuff really. So, it is limiting their life now. Well, my life has been limited from doing everything that I used to do.

SPEAKER_1
[00:17:32,913]washing, cooking, trying to do the dishes. So it's it's it's just it's just a limitation. It just limits it. Yeah.

SPEAKER_0
[00:17:45,913]Okay.

SPEAKER_0
[00:17:47,393]So being told there were no further surgical options as you explained before, it

must be an incredibly difficult thing to hear from the professionals who are supposed to help you. How are you managing that and has the NHS supported you through?

SPEAKER_1
[00:18:06,433]The the NHS is not going to support me really because

SPEAKER_1
[00:18:12,693]My legs swell a lot when I sit down. And sometimes I don't want to be in bed.

SPEAKER_1
[00:18:21,213]'Cause sometimes I'm already tired of the bed. I just want to sleep out. But they just gave me a normal chair.

SPEAKER_1
[00:18:29,453]Not a recliner to lift your legs. They don't give you a stool to lift your legs. So.

SPEAKER_1
[00:18:40,293]That's the problem with it. So, a therapist is supposed to come and see me to see if I need a reclining chair because I can move. I'm not because I can move around now. I'm not entitled.

SPEAKER_1
[00:18:56,123]But when I couldn't move around, they still gave me the same chair.

SPEAKER_1
[00:19:02,543]when I couldn't move around. So those times when I couldn't move around, I was entitled but I still didn't get it. So now they say I'm not entitled.

SPEAKER_1
[00:19:15,713]So basically

SPEAKER_0
[00:19:19,673]He felt he'd given up on you.

SPEAKER_1
[00:19:22,153]until my hip hurts, then I go into bed and then I'm in the bed with the pain and then oxygen and morphine as usual and so that's the way my life goes.

SPEAKER_1
[00:19:37,333]because they don't understand that sitting down for a period of time, your hip.

SPEAKER_0
[00:19:44,003]Yeah.

SPEAKER_1
[00:19:44,983]every day 'Cause I can't go shopping anymore. I can't walk the mall on my own anymore. I can't do anything on my own anymore.

SPEAKER_1
[00:19:54,353]I've got to wait until my sister's available because she's working as well.

SPEAKER_0
[00:20:00,743]Yeah.

SPEAKER_0
[00:20:03,843]I can't comprehend how you even live it. You've also had serious respiratory complications including the pulmonary embolism. How has that changed things for you on top of the physical pain of the sickle cell? That's like an additional thing.

SPEAKER_1
[00:20:26,723]É preciso que eu faça isso mesmo. but I just try not to think about it because I was in a really deep depression.

SPEAKER_1
[00:20:37,393]And I don't want to go back to it, so I try not to think about it. I'm trying to accept life.

SPEAKER_0
[00:20:52,293]You're really brave to cope with this every day.

SPEAKER_1
[00:20:55,903]You're welcome.

SPEAKER_0
[00:20:56,633]Christmas

SPEAKER_1
[00:20:57,073]If not, I'm gonna be at home just crying.

SPEAKER_1
[00:21:02,953]When I cry, my heart rate goes up.

SPEAKER_0
[00:21:05,783]Hmm

SPEAKER_1
[00:21:06,593]When my heart rate goes up, my head starts to hurt. And then everything started to trigger off again and then I didn't know it, I'm in the hospital and so I try not to think about it.

SPEAKER_0
[00:21:20,643]Okay.

SPEAKER_1
[00:21:22,423]Most of the best ones are, I'm glad the council's done nothing.

SPEAKER_0
[00:21:28,223]just get on with it. Nah. So what does a typical day look like for you right now, managing your own health on 24-hour oxygen?

SPEAKER_0
[00:21:41,523]If you describe a day with crisis and a day without crisis, how does it look like for you?

SPEAKER_1
[00:21:48,683]A day with prices. I'm just in bed. Can't do nothing. I'd rather stay at home than to go to the hospital.

SPEAKER_1
[00:22:03,363]Chiar dacă nu-mi place foarte tare, este un sport greșit.

SPEAKER_1
[00:22:08,503]Yes, they have medication that relieve the pains quicker than than morphine at home, but otherwise than that

SPEAKER_0
[00:22:24,043]Chris, you're just taking it one day at a time, see how it goes.

SPEAKER_0
[00:22:30,233]Sounds really, really stressful. Yeah.

SPEAKER_0
[00:22:35,923]So we're going to move on. Obviously there's a lot going on with you. The hospital can only do so much. Same with everybody else around you, but looking back over the 46 years of living with sickle cell, what do you wish had been done differently? By the NHS... by the NHS first of all.

SPEAKER_1
[00:23:03,813]I don't know what to say about the NHS, but I wish I could see people with sickle cell who don't when it doesn't show on their hips, it doesn't show on any of their joints.

SPEAKER_1
[00:23:13,893]They get a transfusion maybe every two weeks. And and and that's about it. If I was like that, I would be okay. But I'm not like that, so

SPEAKER_0
[00:23:27,853]So what would you wish the NHS had done differently from the moment...

SPEAKER_1
[00:23:32,613]It's just a joke sometimes.

SPEAKER_1
[00:23:36,073]there. If I get sick now and I cannot manage at home, I used to go to Dudley Road at the Sickle Clinic. Now they moved it to that bigger hospital that they built up, and a metropolitan somewhere like that.

SPEAKER_0
[00:23:54,263]Yeah.

SPEAKER_1
[00:23:54,913]if you go if you go in there you got to call if you're in pain all night and you cannot manage no more you got to call them before you can go in to see if there's a bed available

SPEAKER_0
[00:24:09,313]bad for you

SPEAKER_1
[00:24:11,663]If you call the ambulance and the ambulance takes you in, they take you to A&E, the doctors look at you and then they jab you in the waiting room for ten hours.

SPEAKER_0
[00:24:28,223]Wait ten minutes.

SPEAKER_1
[00:24:29,823]ten hours sitting in the waiting area in pain and nothing else.

SPEAKER_1
[00:24:38,843]And when you finally see a doctor, it's like it makes no difference. So.

SPEAKER_0
[00:24:45,103]Just been making

SPEAKER_1
[00:24:46,643]Hello.

SPEAKER_0
[00:24:48,343]Okay, so what do you want the doctors, nurses, and healthcare professionals to understand about what it feels like to be in your position?

SPEAKER_1
[00:24:57,883]you're never going to know until they have a relative with sickle cell or their child or something with sickle cell, then they will understand what we go through.

SPEAKER_1
[00:25:14,813]They'd never been enough.

SPEAKER_0
[00:25:16,543]I wish they knew.

SPEAKER_1
[00:25:18,683]Well.

SPEAKER_0
[00:25:21,053]which

SPEAKER_1
[00:25:22,673]we can only wish and hope, but 95% make no sense. I thought doctors should be the caring ones and

SPEAKER_0
[00:25:34,013]Yeah.

SPEAKER_1
[00:25:35,323]with empathy and wisdom. They don't have it.

SPEAKER_0
[00:25:39,313]So if they were here now, the doctor and the nurses, you want them to know.

SPEAKER_1
[00:25:45,273]they wouldn't do nothing because they're gonna say

SPEAKER_0
[00:25:47,223]I mean, you have the opportunity.

SPEAKER_1
[00:25:48,703]want to say they can't do nothing. Basic color. They just come over, look at you and give you morphine and that's it. Just so they can't do anything.

SPEAKER_0
[00:25:59,713]Yeah, but would you have something you want to tell them?

SPEAKER_1
[00:26:07,143]Click. they need to go back to university to study.

SPEAKER_0
[00:26:10,883]Just send it again. Alright.

SPEAKER_1
[00:26:14,423]'Cause most of them don't know.

SPEAKER_0
[00:26:16,343]don't seem to know what they're doing. Hello Right.

SPEAKER_1
[00:26:21,003]Or they know and they don't care which one of the two things. Either they don't know or they know and they don't care. So...

SPEAKER_0
[00:26:28,663]Yeah.

SPEAKER_1
[00:26:30,843]Basically, that's it.

SPEAKER_0
[00:26:32,863]Yeah. That's still even harder to deal with. So what has kept you going through the hardest of times?

SPEAKER_1
[00:26:41,173]Mom Mama, c'est ce

SPEAKER_0
[00:26:48,913]They kept you going.

SPEAKER_1
[00:26:53,713]Yeah, talk to him a lot.

SPEAKER_0
[00:26:56,693]Yeah, they keep encouraging you, being there for you.

SPEAKER_1
[00:27:00,553]social media

SPEAKER_0
[00:27:02,333]Yeah

SPEAKER_1

[00:27:03,573]entertainment

SPEAKER_0
[00:27:04,403]to occupy yourself, yeah. Okay. Just one last question. What message would you give to someone who has just been diagnosed with sickle cell disease?

SPEAKER_1
[00:27:17,293]It's alright.

SPEAKER_1
[00:27:18,883]You can't do anything about it. It's just, it's just, it's just, it's just life. So you just carry on living a life if you can. If you're okay doing whatever and not feeling sick, carry on. Because nothing is there to change. I used to be helping down all about doing everything.

SPEAKER_1
[00:27:46,993]So, I wouldn't change anything. Cuz I didn't enjoy my life then, but

SPEAKER_0
[00:27:56,573]C

SPEAKER_1
[00:27:57,783]up until 2023, even though I had those surgeries before, I was back to normal, living my life, working and traveling, doing whatever I wanted to do.

SPEAKER_1
[00:28:11,233]But until 2023, that's it. I want to go on holiday. I've got to get Dr. Nott. Most of the doctors, if I listen to them, I don't do nothing, so

SPEAKER_1
[00:28:24,893]If I listen to them, I never travel, sir.

SPEAKER_1
[00:28:31,813]My aunt died last year in Jamaica. November she buried January last year. Mister.

SPEAKER_1
[00:28:41,883]And if I'd listened to them, I would have never gone to the funeral.

SPEAKER_1
[00:28:48,983]Because they said I'm not supposed to be traveling.

SPEAKER_1
[00:28:53,343]If I'm not, but you're not doing anything and I can't sit there and say I'm not doing anything. So.

SPEAKER_0
[00:29:01,073]You can socialize.

SPEAKER_1
[00:29:03,413]Look at the girls. So, I went. I take my hydrogen and wind.

SPEAKER_0
[00:29:09,663]How was it for you?

SPEAKER_1
[00:29:11,563]It's alright.

SPEAKER_0
[00:29:12,623]Wir machen es doch okay.

SPEAKER_1
[00:29:14,423]Is that okay? I feel much better. environment

SPEAKER_0
[00:29:19,603]Okay.

SPEAKER_1
[00:29:20,313]different

SPEAKER_1
[00:29:22,753]But the problem with Jamaica is the medical system is not good. That's the only problem, so

SPEAKER_1
[00:29:38,713]Macbook When you're here, even though the medical system here is not good, it is much better. It's better. Yeah.

SPEAKER_0
[00:29:49,903]At least they have facilities.

SPEAKER_1
[00:29:53,543]In Jamaica, I want to have this. 'Cause nobody's, well, I don't have the money to pay for it.

SPEAKER_1
[00:30:03,423]So.

SPEAKER_0
[00:30:08,123]Okay. His story is truly moving and that's the end of it, but it's a

SPEAKER_1
[00:30:15,623]Once you can just stabilize. Yeah. There's no point. Sometimes I feel depressed, yes. Sometimes I feel down, yes. Sometimes I just get fed up, yes.

SPEAKER_1
[00:30:29,063]My life is to wait on people. And I'm an independent person. I like to go and do my own stuff. So my life is to wait. And that's the problem.

SPEAKER_0
[00:30:42,553]microwave

SPEAKER_1
[00:30:44,083]I don't like white tea.

SPEAKER_0
[00:30:50,353]Well, Tamara, thank you so much. Is there anything else you'd like to add for the people who are going to listen to your story?

SPEAKER_1
[00:31:02,113]No, just when you have sickle cell, you just have to accept it.

SPEAKER_1
[00:31:10,763]Nobody wants to accept sickness. So.

SPEAKER_1
[00:31:15,423]I tell myself I didn't go to the shop and buy it because if it was selling, I wouldn't buy it, so that's the last thing I spend my money on buying sickness.

SPEAKER_1
[00:31:28,703]Kinniku

SPEAKER_1
[00:31:32,743]Yeah.

SPEAKER_0
[00:31:34,903]Okay

SPEAKER_1
[00:31:36,023]See, I got to be. Even though this is, I don't think these arteries are 100%, but I gotta be checking them.

SPEAKER_0
[00:31:48,563]Yeah.

SPEAKER_1
[00:31:49,323]Yeah, so.

SPEAKER_0
[00:31:53,003]Well, Tamar, thank you so much for coming to share your story with us today. These will change a lot of people's lives once we compile everything. We're really, really, really grateful that you came all the way despite the difficulties. So thank you. Yeah, thank you so much.