Melissa Audio.mp3

Sickle Cell Stories: A Parent's Perspective on Care and Management

Summary Of Each Speaker

SPEAKER 0 (Melissa Mbakop): A mother and nurse who shared her experience raising a son with sickle cell. She contributed detailed insights into the daily management of the condition, the importance of early diagnosis, and the emotional resilience required to navigate the healthcare system as a single parent.

SPEAKER 1 (Interviewer): Facilitated the "Sickle Cell Stories Then and Now" project. They focused on gathering qualitative data regarding the evolution of medical care, the effectiveness of school support systems, and the mental well-being of caregivers.

Key Points And Decisions

Diagnosis and Treatment: Melissa noted that prenatal screening and her professional background as a nurse allowed her to be mentally prepared for her son's diagnosis. Prince is currently managed with a regimen of penicillin, folic acid, and hydroxychloroquine, which has successfully reduced his hospital admissions to approximately once per year.

Crisis Management: The consensus reached is that proactive home management—including hydration, pain relief, and close monitoring is the primary strategy for handling crises. Melissa prefers self-transport to the hospital over using ambulances due to timing concerns.

Support Systems: Both speakers acknowledged the critical role of a strong support network. Melissa confirmed that a formal care plan is active at her son's school and that she maintains open communication with his medical team to ensure consistent care.

Care Evolution: Melissa observed that the quality of care for children with sickle cell has improved significantly over the last decade, though she remains hopeful for future medical breakthroughs that could eliminate the disease.

Next Steps

SPEAKER 0 (Melissa): Committed to maintaining the current home-based care routine, continuing to advocate for her son’s needs within the school system, and preparing for the eventual transition to adult healthcare services.

SPEAKER 1 (Interviewer): Will synthesize these findings into the "Sickle Cell Stories Then and Now" project to help identify gaps in support and highlight successful management strategies for other families.

SPEAKER 0

[00:00:00,000]All right.

SPEAKER 1
[00:00:02,029]Hello Melissa, good afternoon. How are you?

SPEAKER 0
[00:00:06,290]I'm fine, thank you.

SPEAKER 1
[00:00:07,510]Okay, it's lovely to be here with you in your beautiful home today. So, today we're going to talk to you about our project Sickle Cell Stories Then and Now. You have a son, Prince, a little handsome man. Can you just tell us how old he is?

SPEAKER 0
[00:00:25,080]Princess Di It's very clear, yeah, it's a big deal.

SPEAKER 1
[00:00:28,130]nice

SPEAKER 1
[00:00:28,830]So we're going to be asking you questions about your experience living with Prince as he has sickle cell. And we just want to understand how life has been, how the treatment has been from when he was born up until now, okay? So if there's anything that you're not comfortable talking about, please let me know. Uh if you want a break, we can take a break. There's not many questions but we'll do the best we can. So I'm going to start with diagnosis and early life experience.

SPEAKER 1
[00:01:00,260]So when did you find out that your son had sickle cell? How was that experience for you?

SPEAKER 0
[00:01:06,480]Well, it's not something I wasn't really aware of. I was already aware while I was pregnant because we did like a test from the mom and dad, so the doctor already told us that there'd be a chance that the child would be having sickle cell. So when he was born, they thought they did the prick test at about a month or two months old, so they had the result that he had sickle cell.

SPEAKER 0
[00:01:30,240]So it wasn't really shocking for me. I was already prepared mentally, so I just had to deal with it. The dad was prepared as well. So we just had to deal with it. just carry on and I will sit till today.

SPEAKER 1
[00:01:42,090]Alright, that was that.

SPEAKER 1
[00:01:43,110]you answered my next question if you were screened during pregnancy or after birth, which is good to know. Yeah. So what kind of information were you giving at the time when this is when Chris was born and obviously they did the prick test. They did a test for newborn screening and it was discovered that he has sickle cell. So that was at birth.

SPEAKER 0

[00:02:08,060]Yeah when he was born.

SPEAKER 1
[00:02:10,160]C

SPEAKER 0
[00:02:10,680]Oh, you mean when I had information?

SPEAKER 1
[00:02:12,260]when when when did you find out

SPEAKER 0
[00:02:14,660]five years when he was born about two months old Yes

SPEAKER 1
[00:02:18,490]Okay, so what kind of information did they give you at that time?

SPEAKER 0
[00:02:21,980]Well I had done my research already, we did so I didn't really get that much.

SPEAKER 1
[00:02:27,990]Okay

SPEAKER 0
[00:02:28,660]but I was already aware, like I said, and I was working as a nurse in an oncology ward stroke hematology, so I had some experience already. I knew how my child would behave when that happens. I could I could tell with the signs, some signs and

SPEAKER 1
[00:02:44,790]Okay

SPEAKER 0
[00:02:45,410]and obviously we had we were quite lucky as well when he started obviously with children's hospital

SPEAKER 0
[00:02:53,500]He had his good consultant, well, he still has the same consultant, she's quite good. And the nurses that worked along with her were quite good as well. So they gave us that information and reassurance as well.

SPEAKER 1
[00:03:05,150]Okay, that's good. Good. And did you feel emotionally, obviously you are a nurse, so you're kind of emotionally prepared with these things. Yeah, yeah. Did you feel like you were

SPEAKER 0
[00:03:16,580]I was yeah, and I'm always emotional about it anyway, so it's never gonna change.

SPEAKER 1
[00:03:20,950]It's okay.

SPEAKER 0
[00:03:21,420]still national about it, yeah.

SPEAKER 1

[00:03:23,830]And do you think it's better to be prepared and know beforehand, like you had the screening during pregnancy, do you think that helped you in preparing?

SPEAKER 0

[00:03:36,760]'Cause they give you the choice.

SPEAKER 1

[00:03:39,420]Okay.

SPEAKER 0

[00:03:40,020]if you want to carry on with the pregnancy or you want to get rid of it. So I said, " I'm going to carry on with the pregnancy. Same with that. So he was quite happy for us to carry on with it.

SPEAKER 0

[00:03:52,060]yeah He wasn't ready to just get rid of the baby just because of sickle cell. I mean it could be worse. It could be anything, so I said no. I will have my baby and I will deal with it.

SPEAKER 1

[00:04:02,190]Lovely. So I'm going to move on to medical care and treatment. What kind of treatment or medications is Prince currently on?

SPEAKER 0

[00:04:09,330]He's got different medications like uh penicillin, which is an antibiotic that he takes every single day for life, and he has folic acid as well, which is every single day for life. He has hydroxychloroquine. And mind you that hydroxychloroquine was prescribed to him, I think when he was... 'cause when he was born, obviously three months went before diagnosing him, he had two medications, penicillin and high and folic acid. And the thing is he was quite poorly most of the time, always in hospital like back, back and forth, back and forth.

SPEAKER 0

[00:04:45,980]and they just found out, you know what? We need to put him on hydrogen sulfide and see if the prices will reduce. And since he was one, he's been on hydrogen sulfide. It's helped actually.

SPEAKER 1

[00:05:01,960]Music

SPEAKER 0

[00:05:02,480]has helped him, yeah he's not been going to hospital like he used to.

SPEAKER 1

[00:05:06,420]That's good to know.

SPEAKER 0

[00:05:07,400]If he has to, it's probably once a year, like once a year, not once a year that he stays in hospital like super long. Okay. He will go for minor problems, not, you know, yeah.

SPEAKER 1

[00:05:20,920]Okay, I was just going to ask how often he gets sick or so once a year which is good.

SPEAKER 0

[00:05:25,860]once a year admissions, I would say, yeah. Once a year he is admitted and then he has sickle like sometimes, not all the time, but sometimes I don't really. He doesn't really have to stay in the hospital, it's just minor. We just do the normal like, we normally do to keep him hydrated.

SPEAKER 1
[00:05:44,700]Yes.

SPEAKER 0
[00:05:45,300]pain relief and

SPEAKER 1
[00:05:46,660]Okay That's good to know. And how often does he visit the clinics?

SPEAKER 0
[00:05:51,330]It's just every two months.

SPEAKER 1
[00:05:52,650]for two months

SPEAKER 0
[00:05:53,400]and he's unblocked his blocked pass.

SPEAKER 1
[00:05:55,510]Have you been considered or have you considered any new treatments? Have they offered you any new treatments?

SPEAKER 0
[00:06:00,930]Not for now, no.

SPEAKER 1
[00:06:02,720]Okay. So, have you found healthcare professionals knowledgeable and supportive?

SPEAKER 0
[00:06:09,260]very

SPEAKER 1
[00:06:10,140]from when he was born

SPEAKER 0
[00:06:11,300]from when he was born I don't think I'll ever change the saucepans.

SPEAKER 1
[00:06:14,590]All right. Yeah, yeah, yeah.

SPEAKER 0
[00:06:16,560]Birmingham children might be quite good.

SPEAKER 1
[00:06:18,770]Okay, so the quiz is ten and you're aware that when he gets to adulthood, is it sixteen or eighteen?

SPEAKER 0

[00:06:27,430]Yeah.

SPEAKER 1
[00:06:28,350]I know it's a long way away. Have you ever thought about transitioning to adult care? Mhm. Yeah. Does that concern you at all?

SPEAKER 0
[00:06:36,810]Not at the moment.

SPEAKER 1
[00:06:38,620]Yeah. We'll cross the road bridge when we get there, I guess. Yeah.

SPEAKER 1
[00:06:41,480]So, are there any differences in the quality of care across different services? And what I mean by this is, obviously he's under the haematology, has he been under ophthalmology or kidney or any other specialist specialty for his sickle cell?

SPEAKER 0
[00:06:59,460]No.

SPEAKER 1
[00:07:00,900]just just um hematology at the moment

SPEAKER 0
[00:07:03,930]mythology at the moment

SPEAKER 1
[00:07:05,900]so move to the next one because that doesn't apply.

SPEAKER 1
[00:07:09,340]So, what does a typical day look like in terms of managing his condition? I mean, when I say typical day, like a day where he isn't in crisis. And obviously you've got three children. What does a typical day look like?

SPEAKER 0
[00:07:27,030]Well, it's quite difficult, it's tough because we don't, we don't get any sleep. I don't get any sleep because I have to be awake to make sure he's alright. I have to just be awake. So, that's how tough it is. I just go back to sleep when he's fine, but yeah.

SPEAKER 1
[00:07:44,040]Do you have to plan meals, hydration or rest differently? How do you do that as a single mom especially?

SPEAKER 0
[00:07:52,250]I'll just carry on as normal. Yeah. I don't make it actually look as bad, but I just carry on as normal because I know it's just for a time.

SPEAKER 1
[00:08:02,150]A musical note plays.

SPEAKER 0
[00:08:02,580]it's not going to last forever, it's just for a time. dass ich book that in my mind and I'm I'm I'm more right.

SPEAKER 1
[00:08:08,450]Are there any precautions you take with the weather or any activity that he needs to engage with?

SPEAKER 0
[00:08:13,720]At the moment, he's not doing any activities like that.

SPEAKER 0
[00:08:17,270]he used to. But because of the weather, because he used to do tennis, that was an outdoor thing. But when it's cold, like winter time, it affects him. So I just said, well, there's no need for him to do it. And so yeah, when he goes to his dad for the weekend sometimes, his dad does football with him.

SPEAKER 0
[00:08:38,240]And in terms of we we and then we just do little activities at home as well. Very good. That's why I've got everything in the house, to make sure that whatever he wants to do, like footfall, we've got everything.

SPEAKER 1
[00:08:50,150]Okay And in terms of his school, is there enough support in place? I mean, do you think he's been supported well enough in school?

SPEAKER 0
[00:08:58,290]Yeah, they're quiet, they're quite aware as well. If anything, they always call me and if anything, I will let them know as well. So

SPEAKER 1
[00:09:05,170]And so the next question is, how do you handle sickle cell crises? Say, let's say he wakes up at 2 a.m., which is for some reason the crisis always comes at odd hours. How do you manage it?

SPEAKER 0
[00:09:22,850]We can send it to all the children.

SPEAKER 0
[00:09:28,710]Well, managing is just to give him pain relief, okay? Make sure he is hydrated, check his temperature, just know, you know, if it's not, you know, if it's not high, if anything, then I take him to the hospital.

SPEAKER 1
[00:09:45,500]Have you ever had to call the ambulance? Yeah. Okay, how was the experience with that? How was your experience with that?

SPEAKER 0
[00:09:52,590]with the ambulance it's quite hard because they don't really come on time. So I don't really bother with the ambulance to be honest with you. I'll just take him myself, just drive. So I put the kids in the car and then drive.

SPEAKER 1
[00:10:03,680]O

SPEAKER 0

[00:10:04,190]and then I will just let the dad know as well that this is what's going on. I'm on my way to the hospital and then he meets us there.

SPEAKER 1
[00:10:10,380]So when the ambulance comes, do you think that they understand sickle cell?

SPEAKER 0
[00:10:17,330]They do understand, obviously, and the next thing will be to go to the hospital. So seeing as I'm already aware and I know what happens, I just take it myself. Take it myself.

SPEAKER 1
[00:10:29,290]My next question is, do you have a plan at home or like when things happen, people say, oh, do you have little things that you do to avoid going to hospital or do you just go to hospitals?

SPEAKER 0
[00:10:41,280]No, no, I don't go straight away. No. I go to the hospital when it's really bad. I do manage it at home myself. Yes. So first thing, I make sure I give him spine relief. Yes. I give him enough water to drink. And I sit with him and I check where the pain is. And if it's anything that I can do, like to massage it, to give him, like sit him up, things like that, I do that first. And if he needs anything else, I just do that.

SPEAKER 1
[00:11:10,460]What's usually his reaction?

SPEAKER 0
[00:11:12,430]we usually stay home for like three days and he's still in pain but not that bad that I have to take him to the hospital. We just stay home. But then when it's really bad, then I have to take him to the hospital because it comes and goes. It depends on how often it comes.

SPEAKER 0
[00:11:27,360]Yeah

SPEAKER 0
[00:11:28,340]depending on how often he comes and obviously I'll start with paracetamol and then I have ibuprofen and then if it gets worse, that the pain is consistent, then I give him morphine. If it doesn't work, then it's an alert. I'll have to just take him to hospital or before I do, sometimes I will just let his nurse know like, um, I'll ring and I'll say, oh, this is what's going on. If it's really bad, then I just go straight away to A&E.

SPEAKER 1
[00:11:55,220]He just mentioned his nose. He has a dedicated nurse.

SPEAKER 0
[00:11:58,500]Yeah

SPEAKER 1
[00:11:59,510]that you can call

SPEAKER 0
[00:12:00,610]Yeah, I have the number that I'll just call.

SPEAKER 1

[00:12:02,650]Yeah, that's brilliant. Yeah. Okay. That's brilliant. And what's usually his reaction?

SPEAKER 0
[00:12:06,930]whenever I go, when it's that bad, and if we go to A&E, they see him quickly.

SPEAKER 1
[00:12:13,080]Piano chord

SPEAKER 0
[00:12:13,660]so we don't have to wait that long. But if it's something that I'm concerned about and it's actually doing the baby, I can take him to the hematologist straight away. And then they'll see him there. If they have to keep him, then they'll put us on a ward.

SPEAKER 1
[00:12:27,740]Okay. Okay, so you believe your experience with him in the crisis has been really good to him taking him to hospital? Yeah. Yeah.

SPEAKER 0
[00:12:34,250]Yeah. So I mean, I live in Stone. It takes me an hour to get there. It's fine.

SPEAKER 0
[00:12:39,290]I mean, we had Stoke-on-Trent Hospital, but I don't think he's used to it. We've been there before and I didn't really have a good experience, so I'd rather just take him to Stoke. I mean, to Children's there.

SPEAKER 1
[00:12:52,020]Okay. And what's usually his reaction when he demonstrates fear, anxiety?

SPEAKER 0
[00:12:58,960]Yeah, it's quite anxious 'cause obviously it's painful and nobody would understand how painful it is apart from him. And he's got siblings and the worst thing is he's just there to cry for no reason, but he's in pain. So when I see him when he's really in pain, I know...

SPEAKER 1
[00:13:18,360]So, the next thing I want to ask is about your emotional and mental well-being and I appreciate that you're doing such a wonderful job as a single mother. I've told you this several times. You've got three children. I don't even know how you do it.

SPEAKER 1
[00:13:32,280]So, how has caring for a child with sickle cell affected your emotional well-being?

SPEAKER 0
[00:13:40,360]I mean, it has affected me emotionally as well because obviously no one would like to see a child in pain and obviously in and out of hospital all the time. Thank God that he's always given me that strength because if not for him, I wouldn't be where I am right now. So it's him giving me that strength, power and energy to do whatever I'm doing for the kids. So it's not just me alone, it's just from him as well. And I've got family friends as well. So if I do need them, they will be there for me to give me that support. So it's not just me. I know I might be far, but I still have people around that would be there for me if I need them.

SPEAKER 0
[00:14:20,210]Usually I like to do my things by myself, but if I do need it, if I'm desperate for help, I will get help. Yeah

SPEAKER 1
[00:14:27,360]I really want to emphasize that it's so important to have a network of people that can support you, you know, if you need it.

SPEAKER 0
[00:14:37,360]Yeah, when I need it because I don't really like to be a burden for someone, but if I really do need it, I'm desperate, I've got people that I can rely on.

SPEAKER 1
[00:14:45,740]Yeah, and you did mention that you are a nurse. Are you still practicing?

SPEAKER 0
[00:14:51,070]at the moment, I'm not really working like that because of childcare. Yeah, because before when Prince was ill, the last time he was admitted.

SPEAKER 0
[00:15:03,680]He was always in pain, so the school would keep calling me. And through with my work and being a single mom, there's no other person to pick him up. So I have to do it. So that means I have to leave work and my son comes first or my kids come first. So I have to just give up because that was a permanent job. I had to give up and go on a ban. So that's work when I need it. Like when I watch out there, I'll go to work. So I do practice only when...

SPEAKER 0
[00:15:33,520]Wallah kan Well when I can't I don't I don't do it. cuz it's snowing Yeah.

SPEAKER 1
[00:15:40,440]But do you feel stress or guilt or sometimes you feel burnout?

SPEAKER 0
[00:15:46,260]No

SPEAKER 0
[00:15:47,160]I would say I used to be very stressed when I was working because I had to juggle both when I was working full-time. The kids' sickle cell, if it's in pain and stuff, I would be stressed because I'm thinking, oh gosh, I need to be with my child, work, they're calling you here and there. So that's when I used to be stressed, but now I'm not stressed at all. So I'm well focused on him, on the kids, so that's just...

SPEAKER 1
[00:16:10,260]Yeah, does Prince talk about his pain?

SPEAKER 0
[00:16:15,040]To me. Yeah, if he's in pain, he knows he has to say it. C

SPEAKER 1
[00:16:19,870]Is he aware of having sickle cell?

SPEAKER 0
[00:16:21,550]Yeah, he's a white

SPEAKER 1
[00:16:23,320]Nog niet, dus ja.

SPEAKER 0
[00:16:24,370]Yeah, we've explained it to him.

SPEAKER 1
[00:16:26,450]Yes. And uh, how has it affected his school and his school life and his friendship?

SPEAKER 0
[00:16:34,110]Well, when he's in pain, he doesn't just go to school because obviously he can't, he can't manage it, he's in pain. So that would definitely affect it, but not that much because when he gets back to normal,

SPEAKER 1
[00:16:46,220]Does this school play catch up? Did they have a school support team?

SPEAKER 0
[00:16:50,390]they do, yeah, so they'll just catch up with him and then when he's fine, we'll just do homework or activities, whatever he's missed out on.

SPEAKER 1
[00:16:57,340]Have you had to advocate for special care at school for him? No, like, are there any care plans or medical...

SPEAKER 0
[00:17:06,000]Well, he's got a care plan in place, yeah.所以就這樣， 你就可以。Okay hospital, there's there's a specialist nurse there.

SPEAKER 1
[00:17:13,480]Yes

SPEAKER 0
[00:17:14,020]in the children's hospital she's done that. So the school, I've sent it to them. So yeah, whichever school he goes to, he has a care plan.

SPEAKER 1
[00:17:20,790]fantastic second, do you feel that teachers listen to you, the school listens

SPEAKER 0
[00:17:26,470]Yeah, they do, and they are aware of it.

SPEAKER 1
[00:17:28,690]Mm-hmm. But my next question is something that you've probably touched on already, the support system. You know, you've mentioned that you have a really good support system, which is good. Do others understand what sickle cell really involves like your family and friends?

SPEAKER 0
[00:17:42,150]Yeah, they do. Yeah

SPEAKER 1
[00:17:44,180]Are you part of any support groups online or local?

SPEAKER 0

[00:17:49,070]Mmm, yeah, like, yes, what your group actually is, yeah.

SPEAKER 1
[00:17:53,240]Glad to hear that. And do you feel there's enough support for parents like you? Yeah. Brilliant. I mean, we're doing our best.

SPEAKER 0
[00:18:02,200]always ready to always ready to hear

SPEAKER 1
[00:18:04,800]Yeah, absolutely. Glatz and I know living with a child with sickle cell or any disability comes with a lot of financial challenges. Are you facing any financial difficulty as a result of

SPEAKER 0
[00:18:19,230]No, I wouldn't say that.

SPEAKER 1
[00:18:21,180]You get emotional support.

SPEAKER 0
[00:18:22,710]Yeah, we're fine. I mean like, there's no yeah. And the dad, like I said, he's also there. to to help so

SPEAKER 1
[00:18:29,590]That's fantastic.

SPEAKER 1
[00:18:30,800]So have you spoken to other parents or older or older people living with sickle cell? How do their experiences compare to, you know, you having a child? Do you think it's different?

SPEAKER 0
[00:18:45,210]Well everybody's different to be honest. So everybody experiences sickle cell differently. Some are in hospital every week, some are in hospital every month, some are in hospital every three months, every six months. So everybody's different. Depends on how your immune system affects the disease. So I would say that's why I would say if you actually follow what you're supposed to do, you should be fine. If you eat healthy, if you drink enough, you hydrate your system, your body.

SPEAKER 0
[00:19:15,380]you should be fine, maybe you have it only once in a while, not all the time. Like, for instance, it's not all the time he has it. He has little bits and bobs here and it's not something that we really have to take him to the hospital. So it comes and goes.

SPEAKER 1
[00:19:27,610]Do you think in my not too fun experience, do you think care is better now for children? I mean, he's ten. I can see he's had some really good experiences. Do you think care is better now for children with sickle cell than before?

SPEAKER 0
[00:19:42,990]To be fair. It's not the same. It's just it's getting there. Yeah

SPEAKER 1
[00:19:49,470]Have you come across any older patients with sickle cell?

SPEAKER 0
[00:19:53,190]I have actually treated a patient near when I was working on this hematology ward. Yeah. Have a nice day.

SPEAKER 0
[00:20:01,470]Yeah, she was about 18 or 19. It was quite difficult for her because obviously she has to leave uni to be in hospital.

SPEAKER 0
[00:20:10,410]It's quite social support as well. My family and my parents, it was good.

SPEAKER 1
[00:20:15,210]separate

SPEAKER 0
[00:20:15,800]I mean, I've also experienced one in France because I do travel like most of the time. We do go there because obviously we have family there and when we are there, there was a time he was ill as well, so I had to go to hospital and then we had this young girl as well suffering from it. And the dad was there explaining to me what they go through and yeah.

SPEAKER 1
[00:20:41,830]What improvement have you seen, if any, in terms of his treatment and his care? And I'm sure you've had some really good standard of care with Prince. What improvements have you seen and what do you think still needs to change?

SPEAKER 0
[00:21:00,290]And medication-wise, it's just the same as I said before. He used to ask, " Why did you not do this to me? He used to be, It's okay. in and out of the hospital when he was young.

SPEAKER 1
[00:21:13,130]Oh, it's okay.

SPEAKER 0
[00:21:14,410]Just asked him to share makeup and I said okay.

SPEAKER 1
[00:21:18,780]bless Right. I'm going to ask again. So, what improvements have you seen from when he was born and now? And what do you think still needs to change?

SPEAKER 0
[00:21:33,660]When he was born, like I said earlier, he used to go to the hospital often, blood transfusions here and there. Now that he's growing, he's probably had blood transfusion only once.

SPEAKER 0
[00:21:48,950]compared to what it was before.

SPEAKER 0
[00:21:51,300]So, I believe that the care is going up, like it's getting better. And what I do or what we do as parents as well, keeping everything like him, everything has to be just okay for him, like food wise, drinking wise. So we make sure he's drinking okay, he's eating well. And I'm not doing things he's not supposed to do, not exposing him to him as well when it's too cold or when it's too

hot.

SPEAKER 1
[00:22:19,520]So, the last couple of questions are hopes and advice. I mean, what are your hopes for your son's future in terms of his health and his care?

SPEAKER 0
[00:22:29,260]My hope is that one day she just finds a medication that will just take it away, just stop it. Because the pain is just horrible I mean, I don't have the paper I can see looking at it, yeah, when you see, you know that this is really bad.

SPEAKER 1
[00:22:43,860]Do you feel optimistic about future treatments or...

SPEAKER 0
[00:22:47,210]I hope and I pray to God.

SPEAKER 1
[00:22:49,550]I mean, what will give you more peace of mind?

SPEAKER 0
[00:22:53,440]More peace of mind is to get rid of those diseases.

SPEAKER 1
[00:22:56,850]Hopefully one day

SPEAKER 0
[00:22:58,330]Yeah, hopefully one day.

SPEAKER 1
[00:22:59,820]And what advice would you give to another parent who has just received a sickle cell diagnosis for their child?

SPEAKER 0
[00:23:05,960]All I would say is just to when you get the news, just be calm and you just deal with it, take it as it comes because it could be worse. Yeah, I can just carry on with it.

SPEAKER 1
[00:23:18,940]I know you were prepared for this, so it didn't really come as a shock when you had prints. What do you wish someone had told you at the start? Is there anything else? bout of health

SPEAKER 0
[00:23:33,770]No, I mean, I like the idea. I like the fact that they told me while I was already far gone.

SPEAKER 1
[00:23:39,570]So do you think every parent should test before... Yeah, so I yeah, important.

SPEAKER 0
[00:23:44,310]yeah, it's very important to get tested so that you know already if you don't want it, then fine. If you want to go ahead with it, you should be prepared.

SPEAKER 1

[00:23:54,130]And my final question is, what small things have helped you cope day to day? Or the little things that help you just survive this and get on with it.

SPEAKER 0

[00:24:05,730]Yeah, 'cause I know I'm on my own, so I have if I don't do it, nobody will do it. Yeah. So I have to do it, I have to deal with it. So just push myself. You need to do it. 'Cause nobody else is going to do it for you. Definitely. And you're a child, they've only got you, so do it.

SPEAKER 1

[00:24:21,170]Fantastic This was beautiful. Thank you so much. Is there anything that you'd like to say?

SPEAKER 0

[00:24:25,400]Não, mas não sei.

SPEAKER 1

[00:24:26,550]That is, that is fantastic. It's a beautiful, beautiful