Vanessa Part.wav

Interview Summary: Sickle Cell Disease Patient Experience

Speaker Contributions

Geraldine Hammond (Speaker 0): Facilitated the interview on behalf of the "Go Sell Stories" project, supported by the National Lottery Heritage Fund. Her objective was to document the lived experiences of families affected by sickle cell disease to improve understanding of care evolution.

Parent Vanessa Solomon (Speaker 1): Provided a detailed account of her daughter's diagnosis in 2019. She highlighted the critical role of the support group "Oscar" in providing knowledge that was not initially offered by healthcare providers. She shared her experiences with hospital care, school support systems, and the ongoing challenges of managing her daughter's condition.

Key Points and Decisions

Diagnosis and Information Gap: The parent noted that the initial diagnosis was a shock and that she received minimal guidance from the NHS, forcing her to rely on Google and peer support groups for information.

Support Systems: The "Oscar" community was identified as the primary source of knowledge, emotional support, and practical advice regarding diet and medication.

NHS Experience: Hospital interactions are generally described as positive and welcoming; however, the parent reported significant difficulty in securing GP appointments.

School Integration: The school has successfully implemented a care plan, including provisions for pain management, hydration, and environmental adjustments during cold weather.

Concerns: The parent expressed anxiety regarding the child's future health, the potential for delayed pain relief during emergency crises, and the difficulty of maintaining a healthy diet for a fussy eater.

Community Value: Both parties agreed on the importance of community support and the necessity of sharing stories to improve the quality of care for future generations.

Next Steps

Geraldine Hammond: Continue the documentation process for the "Go Sell Stories" project to ensure diverse patient experiences are captured for the National Lottery Heritage Fund.

Parent: Maintain engagement with the "Oscar" support group to navigate future challenges and continue seeking advice from experienced parents and medical professionals within that network.

SPEAKER_0

[00:00:01,906]Okay, so we've started again. So thank you so much for being here. Uh, I mean, for having me and for agreeing to share your experience with us. My name is Geraldine Hammond. I work for Plasmas. And I'm interviewing on behalf of the charity in our project to sell stories. The name now, it's supported by the National Lottery Fund, just Heritage Fund. Yeah.

SPEAKER_0
[00:00:27,886]So the project is about capturing the real experiences of people whose lives have been touched by sickle cell disease. So that we can document how care has changed over the years and make sure every kind of experience is there.

SPEAKER_0
[00:00:43,456]Your story is really important to us. Your daughter was born in 2019 and her diagnosis came through the newborn screening, which has been in place since 2004. So it's just a few years after. You were part of one of the most recent chapters in the history of sickle cell care in the country, and your perspective on what that experience has been like is exactly what we need. It's very intriguing.

SPEAKER_0
[00:01:14,546]So there are no wrong or right answers, just having a simple conversation. Please speak naturally in your own words. You can take your time and pause. We can stop the whole thing if you're not comfortable at any time. Or we can skip any questions that you're not comfortable to answer. Alright. Thank you.

SPEAKER_0
[00:01:37,086]So do you have any questions before we start? Yeah, I'm good. Okay, let's get

SPEAKER_0
[00:01:49,946]We're going to start with the diagnosis first, okay? Can you tell us about the moment when you found out your daughter had sickle cell disease through the newborn screening? What was it like and how did you feel?

SPEAKER_1
[00:02:05,336]To be honest, it was all new to me. I didn't know anything really about sickle cell. Just the only thing that I knew was that I had sickle cell trait. So that's the only thing I knew about it and because I've got the trait, you don't really experience stuff like...

SPEAKER_1
[00:02:22,596]with the full-blown thing. So, um yeah, I didn't know much about sickle cell. Um, so it was all a shock to me to be honest. Um, and yeah, gradually over the years I've learned, you know, through people, through my own experiences and stuff like that. So,

SPEAKER_0
[00:02:38,186]Yeah. So how did the NHS support you in those very early days after the diagnosis? Did you feel informed, guided, looked after?

SPEAKER_1
[00:02:49,466]Um, no, not really no. Um, I didn't get much help to be honest. Um, even from the um healthcare visitors, obviously they just do the whole newborn checks and stuff like that, but they don't really like, you know, talk about, you know, the illness and stuff like that. So um, much of everything that I know is, you know, through, you know, um Google and, you know, hearing from other parents. So joining Oscar was a lot of help. Um, and that's where I gained all my knowledge from, from other carers and parents. So yeah.

SPEAKER_0
[00:03:26,686]Oh, I can't hear. Right. So what did you know about sickle cell disease before your daughter was diagnosed? Did you have to learn everything from scratch? I know you mentioned the cure that you then Googled, but can you tell us more?

SPEAKER_1
[00:03:41,866]Um, well like I said, um, I didn't know much about sickle cell and disease. Um, yeah, so like I said, it was just a whole shock to me. Um, yeah.

SPEAKER_0
[00:03:57,226]How did your family respond when they found out? Was there good support around you?

SPEAKER_1
[00:04:05,496]Um, again, I think it was a shock to most of my family members and my partner as well was basically in the same boat as me, not really knowing much about sickle cell. Um, but yeah, no, in general, sorry, in general, um, yeah, had a kind of okay support system, but yeah, Aska was really the best, um, what can I say? Um, yeah, just most knowledgeable, you know, getting all my information from Aska.

SPEAKER_0
[00:04:40,916]Mascara Okay. Okay, so we move on to the experience of the NHS. You

SPEAKER_0
[00:04:48,136]and comes over with this. So overall, how would you describe your experience of the NHS care for your daughter so far? What has stood out particularly good for you?

SPEAKER_1
[00:04:58,506]Um, pretty much we haven't had any real um, you know, sickle cell crisis. Um, just one um recently in March, but other than that we just go for check-ups at the hospital. Um, yeah, the staff are very um nice and yeah, when we go in, they make us feel comfortable. Um, don't really have any negative feedback on the NHS and when we go and visit the hospital. So um, yeah, everything's pretty much straightforward. We go in, she gets her checks and um, yeah, much.

SPEAKER_1
[00:05:38,686]pretty much in and out

SPEAKER_0
[00:05:39,936]in and out. Yeah. Was there any particular moment that caught your attention about positivity? Is there any particular moment you'd like to share?

SPEAKER_1
[00:05:49,026]um, just like the kind of consultation bit at the end when we go for our little checkups. Um, yeah, they just make us feel, you know, calm and welcomed and they listen, you know, obviously ask, um, is there anything wrong, um, or anything that she's, anything that's happened to her. Um, so yeah, that's when I get to express, um, what I go through and then they offer support as well. Um, in my case, um, I was dealing with, um, some housing issues.

SPEAKER_1
[00:06:25,756]And they did actually um help me with a couple of useful information and numbers, so um yeah, they have helped me out quite a bit to be honest with other things other than the sickle cell blood. Um yeah.

SPEAKER_0
[00:06:40,246]Yeah, it's good to know. Thank you so much.

SPEAKER_0
[00:06:43,016]Well, have there been any moments at all or even the smallest one where you felt things could have been handled better or where you wished you had more support or information?

SPEAKER_1
[00:06:56,866]Um, the only thing that I can say 'cause we've only had one hospital visit, um, is that, um, one of her monitors just kept on going off and just like calling for a nurse. Obviously I know nurses are, you know, pretty much rushing around and have more than one patient to deal with, but, um, yeah, I just felt like things, um, could have been a little bit better. Um, but other than that, it was, it was fairly okay. We didn't have to stay too long, it was like four days, so. Um, it was pretty much okay and yeah, no real complaints to be honest. No.

SPEAKER_0
[00:07:33,616]Okay, that's good to know. Okay. How have the different healthcare professionals you have encountered, like the GP, specialist nurses, treated you and your daughter? Have you felt heard and respected throughout the process?

SPEAKER_1
[00:07:49,776]Um, so when it comes to GP, um, it's a bit of a headache. Um, just trying to get appointments can never get through. Um, and if you do get through, there's no appointment. So, um, it's very hard to get an appointment if she needs one. Um,

SPEAKER_1
[00:08:15,486]Can't really say. Um, I can't think of anything else. Um.

SPEAKER_0
[00:08:21,366]The specialist analysis.

SPEAKER_1
[00:08:25,306]I'd say we don't have too many doctor visit, GP visits. Um, yeah, I can't really say.

SPEAKER_0
[00:08:37,566]Okay. Right, so how has your daughter's sickle cell been managed day to day? Do you feel confident in the guidance you have received?

SPEAKER_1
[00:08:49,106]Um yeah, like I said, I mean I'm gonna mention Oscar a lot because they are a lot of help. Um have you known anytime I need help, um there are people and stuff that I can talk to. Um so um yeah, everything's um

SPEAKER_1
[00:09:08,516]a lot of positivity really. Like I said, she hasn't had many crises. Um, day to day, it's hard. Um and I mean, yeah, I could do with learning a bit more and you know, um more have a fussy eater as well. So it's a bit hard and challenging to try and get her eating a healthy balance. So um yeah, speaking to other

SPEAKER_1
[00:09:36,416]members of the group, um are a lot of help because they do advise a lot of stuff and a lot of um a lot of like healthy recipes and stuff like that that you can try, so um yeah.

SPEAKER_0
[00:09:53,616]Good. Okay. So we're moving on to raising your daughter. How has having a daughter with sickle cell disease affected your family life and your daily routine?

SPEAKER_1
[00:10:07,006]Um, honestly it is a bit stressful, um bit scary at times. Um, like I said, challenging because I do have a fussy eater. She's six so, you know, she's still... um she has an older brother as well so she wants to do most things like her brother, which includes um, you know, unhealthy eating and stuff like that.

SPEAKER_1
[00:10:34,296]So, um, it's a bit hard to, uh, you know, get her to stick to a healthy balanced diet, but um, yeah. Um, for me, yeah, it's scary. Um, when she, 'cause she's in pain the majority.

SPEAKER_1
[00:10:53,096]of the time, most days when she goes to school, I do get a phone call from school just saying that she's in a little bit of pain. Um, so yeah, it's just, yeah, a bit stressful. Um, hard at times, I don't know 100% the correct things to do and the correct things to put in her body, you know, like, um, I'm very much, um, try and do natural, a lot of natural things and natural herbs and stuff.

SPEAKER_1
[00:11:22,266]But yeah, most of the time it's just like, what do you listen to and you know, what's going to help her, what's going to, you know, make her better or get her through the day at least, you know. So yeah, it's very challenging. It is. Yeah.

SPEAKER_0
[00:11:35,306]good So, have you explained sickle cell to your daughter at her age so that she understands what it means for her?

SPEAKER_1
[00:11:44,336]So yeah, I definitely have. Um, I feel like it's very important as she's growing up, um, trying to understand the way her body works. Um, but yeah, at this moment in time, I don't think she quite understands how serious it is. Because like I said, she does follow her brother and wants to do everything her brother does. So, um, yeah, it's a bit hard because yeah, I don't think she quite understands how serious it is. But yeah, for the most part, she is healthy and she's well and she, yeah, gets to do things, you know, like a, uh, I don't like using the term normal, but you know, any kid her age.

SPEAKER_1
[00:12:25,046]Hehehe.

SPEAKER_0
[00:12:27,016]Okay. So, how has the school responded to her condition? Have they been supportive and well-informed? Do they know what to do in difficult circumstances?

SPEAKER_1
[00:12:40,456]So, at the beginning, I think 'cause she didn't really, you know, obviously when they're younger there's, you know, less crises and stuff like that sometimes. So, um, there wasn't really much to worry about, but there was a care plan in place from the start. Um, but as she's got older and she's experiencing a bit more pain and stuff like that, they are more helpful. Um, they um, I send her in um with a water bottle, but she will drink that, so they provide her bottles of water throughout the day if she needs it.

SPEAKER_1
[00:13:10,796]um they have gone over pain meds, um if she needs it in school, um and stuff like if she does have a fall not to put ice packs on her and stuff like that. So they know all that and also um fire drills when you know if it's colder days, you know they're not allowed to grab their stuff but they will grab a blanket for her. So that's um that's good to know that they've got things like that in place for her.

SPEAKER_0
[00:13:38,406]That's really good to know.

SPEAKER_1
[00:13:40,486]Yeah, they are really... They were good schools. Ah, sorry. Good school. I can't talk any more.

SPEAKER_0
[00:13:47,006]Yeah. Okay. So what worries you most about your daughter's future with sickle cell disease?

SPEAKER_1
[00:13:57,046]just that she's just gonna experience pain along the way and it makes me sad, you know, that I mean obviously, you know, people with sickle cell can live a normal life, but you know, there's gonna be challenges that she's gonna experience. Um, uh, yeah. So, yeah, it's a bit worrying, a bit sad, but you know, I just gotta stay positive, I guess.

SPEAKER_0
[00:14:23,026]Ahem.

SPEAKER_1
[00:14:23,826]And just guide it basically as best as I can.

SPEAKER_0
[00:14:27,516]Hope for the best.

SPEAKER_1
[00:14:29,376]Yep, definitely.

SPEAKER_0
[00:14:31,106]Okay. So we're moving on to lessons of the whole experience. What do you know or what do you know now about sickle cell disease and navigating the NHS that you wish someone had told you at the very beginning when she was first diagnosed?

SPEAKER_1
[00:14:49,726]Say that again, sorry.

SPEAKER_0
[00:14:51,966]So what do you know now, like new information that you wish you knew back then, that somebody didn't tell you?

SPEAKER_1
[00:15:01,956]just how serious it could actually be because nobody actually told me how serious sickle cell um could be. Um so like I said, I gained a lot of knowledge through Oscar and the parent's carers. Um yeah, um also how challenging um you know, dealing with the NHS can be because I've

heard a lot of stories as well, how you know, not great

SPEAKER_1
[00:15:31,556]experiences visiting the NHS as well. So, um that scares me a bit but as I said, um I haven't experienced that for myself. So, yeah, that's a bit worrying that, you know, um carers, parents, um and um you know, um sickle cell, um you know, people with sickle cell, sorry, um the challenges they have to face. So, yeah, that, yeah.

SPEAKER_1
[00:16:01,166]it it scares me a bit because um I heard there's a lot wrong as well with the NHS, not enough help and stuff like that when um people sickle cell have crises and stuff like that, they're not really treated how they're supposed to be treated or seen as soon as they should be or dealt with um the way they should be. So also I've heard that um people actually have to tell them how to treat them, which should be the other way around. They should know what to do and stuff like that. So um yeah.

SPEAKER_0
[00:16:34,386]Okay, I know you've mentioned Oscar. So the next question basically covers like, can you tell us if you have um connected with other parents of children with sickle cell disease?

SPEAKER_0
[00:16:49,676]has that community made a big difference

SPEAKER_1
[00:16:54,296]a hundred percent, yeah, I wouldn't, I don't think I'd be where I am if, um, it wasn't for other parents with sickle cell, um, with kids with sickle cell. Um, yeah, like I said, very knowledgeable. Um, there's also, um, mothers that are nurses themselves, so they can, like, any medication or any injections that, you know, they offer my daughter, I do seek advice because, oh,

SPEAKER_1
[00:17:25,356]you know, obviously Google it and stuff like that, but yeah, hearing it from, you know, somebody in that field is, um, it makes me feel a bit better. It does make me feel better. Um, yeah.

SPEAKER_0
[00:17:38,436]Yeah. Okay, great. Okay. Has your experience changed how you think about the NHS or about the support available for families like you?

SPEAKER_1
[00:17:50,256]Yeah, I think that's it. Yeah, it's just a bit worrying. Um about how challenging it may be if I'm in that position and where we do have to go in and for a more serious, um, serious, you know, situation. Um, yeah, it's just overall worrying.

SPEAKER_0
[00:18:12,916]What worries you most?

SPEAKER_1
[00:18:16,816]Like I said, just the stories that I heard, just them not dealing with them the way they're supposed to be. Um, you know. Um, giving them pain relief, you know, pretty much straight away, you know, I heard that it's pretty much delayed sometimes. So, um, yeah, 'cause you know, obviously I know sickle cell pain crises can be a lot. It can be very painful, so just thinking that people are in pain for long periods of time, um, yeah, it's very sad.

SPEAKER_0
[00:18:52,866]Okay. So moving on to the future, have you heard of gene therapy?

SPEAKER_1
[00:18:58,166]I have heard a bit about it, yeah, definitely have heard a bit about it, yeah.

SPEAKER_0
[00:19:02,486]Okay, so gene therapy for sickle cell disease has now been approved. Oh, yeah. What does that mean to you as a mother of a young child with a condition?

SPEAKER_1
[00:19:12,666]that there's hope that, you know, they can live a healthier, you know, life and a life without worry and I'm paying.

SPEAKER_1
[00:19:28,336]Thank you.

SPEAKER_0
[00:19:30,776]So what do you hope your daughter's experience of sickle cell disease will look like as she grows up compared to the experience of the older generation?

SPEAKER_1
[00:19:43,116]Um, I guess there's more information out there. Um, 'cause I have heard of, um, like, that like older people, um, with sickle cell, um, them ex, you know, their experience and, you know, doctors not knowing much, you know, knowledge about sickle cell. So, I can imagine that it was extremely hard back then, um, dealing with their pain crises and stuff like that. So, um, yeah.

SPEAKER_0
[00:20:15,876]Thank you. Now, what would you say to another parent who has just found out through newborn screening that their baby has sickle cell disease?

SPEAKER_1
[00:20:29,016]That's a hard one. Um, you know, like there'll be challenging times. There'll definitely be challenging times, but um, it's kind of hard to say because you know, some people have more

SPEAKER_1
[00:20:46,506]more experiences, you know, more sickle cell crises, more um trips to the hospital and stuff like that, and then other parents might not have as much, you know, um much to deal with and much to go through and stuff like that, but um yeah, there I can just say that there is help out there. There is definitely help out there and there's a community of people, quite a couple of communities of people that will, you know, you can get support off, um and yeah, just guide you through it as well, yeah.

SPEAKER_0
[00:21:21,546]Yeah, so they're gonna be okay.

SPEAKER_1
[00:21:23,406]No, definitely a cause, yeah.

SPEAKER_0
[00:21:26,606]Yeah, so that's the end of it. So thank you so much. The experience of what good care can look like is just as important as any other story in the project. We are extremely grateful

for your time. Thank you. Thank you.

SPEAKER_0
[00:21:42,496]Okay