Airing Pain Programme 86: Sickle cell disease

Patient and clinician perspectives on living with Sickle cell disease and the importance of a multidisciplinary approach.

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An estimated 15,000 people in the UK are living with Sickle Cell disease and at least 250,000 are carriers. Dr Elizabeth Rhodes explains the causes and symptoms of the genetic blood disorder, the areas where it is most prevalent and who is affected.

One such patient is Khadijat Jose, who describes her experiences growing up in Nigeria and why being a carrier of the disease is an advantage in countries with Malaria. For those with the condition however, each day can bring severe pain often requiring admission to hospital. Dr Oliver Seyfried highlights the life-limiting effects of this pain, especially on young people, and the challenges it poses in all spheres of life.

Self-management is therefore hugely important for those with Sickle Cell disease, whether the pain experienced is mild or severe. Paul discusses the different approaches taken by the Red Cell Pain Management team at St George's Hospital with clinical psychologist Dr Jenna Love and specialist physiotherapist Rebecca McLoughlin. Both emphasize the importance of being able to tackle sickle cell pain from an emotional and psychological perspective as well as a physical one.

Paul Evans: This is *Airing Pain*, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans, and this edition has been funded by donations from Pain Concern's friends and supporters.

Khadijat Jose: There was one time I went to North Wales and I wanted to climb Snowdonia, and I told them that I couldn't. And then they said 'Why? Why can't you climb Snowdonia mountain? C'mon it's just a thousand/ eight hundred and something metres' and I said I couldn't that I had a condition called sickle cell disease.

Dr Elizabeth Rhodes: Sickle cell disease is an inherited disorder, so it's a disease or disorder that people are born with. Basically your haemoglobin structure is different to what it should be when you're born, and this means that your red blood cells don't work in the same way. They don't live as long and so you're often very anaemic.

Dr Oliver Seyfried: I don't think there's a condition that quite creates such suffering from cradle to grave as sickle cell disease.

Paul Evans: It's very difficult to assess the number of people who live with sickle cell disorder in the UK. But based on available data, the Sickle Cell Society estimate that there are around 15,000 people living with the it in the UK, and there are at least 250,000 carriers. Sickle cell disease is a disorder of the blood. Dr Elizabeth Rhodes is a consultant haematologist at St. George's Hospital in London. She specialises in looking after people with sickle cell disease.

Dr Elizabeth Rhodes: Within your blood, you've got white blood cells that fight infection; platelets that are the small sticky cells that make sure you don't bleed or clot too much if you've got the right number; and then red blood cells carry the oxygen and the iron around. So they take the oxygen to your tissues that need oxygen.

Paul Evans: So if they're not functioning correctly what happens?

Dr Elizabeth Rhodes: So what happens in sickle cell is that they don't live for very long, they get destroyed very early. So a normal red blood cell will live for about 120 days, about three months, and in sickle cell disease it can be as short as two weeks. And so you get all sort of the broken down bits of red blood cell in your blood, and also the red blood cells are a funny shape. And so they don't work as well and they get a bit stuck, and your blood flow's quite sticky. So what happens is you bone marrow, which is the factory that makes blood, is working many many times harder than it might do otherwise. So you're always producing red blood cells to carry enough oxygen around, and then your body has to process and dispose of the bits that are broken down as well, so you pass that out through your kidneys and your feces as well.

Paul Evans: And what does it mean to the patient?

Dr Elizabeth Rhodes: What they often notice is they're anaemic, so they feel quite tired or short of breath at certain times. But the main problem that patients with sickle cell disease get is they get problems with pain. And that's probably because the blood flow is so

disrupted and those blood cells don't work the blood is stickier, you get less oxygen delivered to the tissues that need it, particularly in bones, and so patients can experience very very severe at times episodes of pain that sometimes require them to go into hospital for treatment.

Paul Evans: So who gets it?

Dr Elizabeth Rhodes: You inherit it so you will need to have inherited two genes that don't work properly and you've taken one from your mother and one from your father. And we see it mostly in patients that have got a family background from western Africa or the Caribbean, and it's the geographical areas actually where malaria is most prevalent. In the UK patients tend to be centred in the big cities, so London and Birmingham, but as, y'know, people move and jobs move and universities move and lives change we're seeing it more and more all around the UK.

Paul Evans: Consultant haematologist Dr Elizabeth Rhodes. Now one of those areas in West Africa where malaria is prevalent is Nigeria. That's where Khadijat Jose is from. She's currently a PhD student at Cardiff University and she has sickle cell disease.

Khadijat Jose: I got the sickle genes from my parents who are carriers. I fall sick quite a lot, it causes pain in my bones, maybe if I don't have good flow. Because sickle cell disease you probably won't have good flow of your cells because your cells are kind of like the letter 'C' and they don't flow properly in your veins, and sometimes they get stuck and that causes episodes of pain. So for me that happens when I'm stressed out, or I'm cold, or I have malaria, which happens to me quite a lot when I'm in Nigeria. So I fall sick, I'm in a lot of pain for days or weeks.

Paul Evans: I was going to ask how long you've had this, you've had this from birth, but when did it become an issue?

Khadijat Jose: According to my Mum, I fell sick the first time when I was about 3 months old. And while I was growing up as far as I remember I used to go to the hospital a lot – I was always in pain from when I was aged 4 to 13 or something. Then it got a bit better. When I was a child it was more intense for me.

Paul Evans: I'm interested in that you said that maybe it showed itself when you were 3 months old, now you won't remember this but what would your mother remember of that?

Khadijat Jose: They thought that my Dad was AA – that's a genotype – and my Mum was a carrier of sickle cell, meaning that they were **not** going to have a child who had sickle cell disease. As far as they [knew] they would only have a child that was a carrier. But they genetic tests were done wrong for my father: he was a carrier as well. So my Mum's side when they found out that I had sickle cell they were really shocked about it cause they weren't expecting something like that to happen.

She just said I used to fall sick quite a lot, and, well, in school I know couldn't do much of the physical activities. If you're a carrier you probably would need to take a few medicines, maybe folic acid, but you can be a carrier and you don't need any medical care because the sickle gene itself was basically a way to be resistant to malaria. So it's actually a good thing! Because the genotypes, we have AA and AS – the S was kind of like the genetic mutation of the body in Africa to fight malaria. So I you have AS genotype then you're fine, you're basically resistant to malaria. But if you are AA, which is when you don't have any sickle gene, you're very healthy but sometimes you fall sick when mosquitoes bite you. But otherwise you're fine. But then if you are sickle cell you have no protection from malaria and then you fall sick all the time. So being AS is the ideal thing, but not being sickle cell.

Paul Evans Let me get that right, so if you're a carrier, you have some sort of immunity against malaria?

Khadijat Jose: Yes you do.

Paul Evans: Khadijat Jose. Now St. George's Hospital, one of the largest in South West London, established a sickle cell pain management programme just a few years ago. The team includes consultant haematologist Dr Elizabeth Rhodes who we heard earlier, a psychologist, a physiotherapist and Dr Oliver Seyfried a consultant in pain medicine and anaesthesia.

Dr Oliver Seyfried: For people who have the serious version of this disease – there is a gradation it's not quite heterogeneic in it's make up, there are people who have it really really badly and there are people who don't have it so badly. Even if you don't have it badly it can really interrupt your school life and your work life, but if you have it badly you are in, 'agony' iss not too bad a word on a daily basis from morning 'til night. And so a serious situation that needs addressing, and people need to realise that when they meet someone with sickle cell disease not only are they holding down their job, bringing up their children, interacting with society in different ways, they're living with this on a day-to-day basis. Now I don't know about you but when I get a tooth ache I become pretty useless, but my toothache has an end – either with antibiotics or the dentist. Sickle cell disease is incurable, it doesn't have an end. And managing it as best we can and enabling people to function is our drive.

Khadijat Jose: The pain feels like someone taking a nail and hitting you with a hammer, with a nail and a hammer like you know when they crucify someone basically [*laughter*] that's how I feel. I'm not sure if that's the general thought[s] about it but that's how I feel when I'm having pain. Like someone's hitting me with a hammer.

Paul Evans: So it's a sharp pain?

Khadijat Jose: It's a sharp pain, yes.

Paul Evans: And that's continuous?

Khadijat Jose: It's continuous, yes. It's continuous for days, but once I have pain relief then that helps to take it away. And sometimes it comes back but I need to completely clear the flow in my veins before I can say 'I am in no pain at all', so it's not just about pain relief for me.

Paul Evans: So when you have an episode how long does that last?

Khadijat Jose: My worst episode was 3 weeks but on average one week, or a few days. If I go to the hospital when I'm having a crisis then I am connected to intravenous fluids. So that helps to hydrate my body, which helps proper flow of the cells in the veins that are probably stuck.

Paul Evans: You go into hospital for every episode?

Khadijat Jose: No, I don't go to the hospital for every episode. There are some episodes that I can manage by myself at home. It depends how bad the pain is for me, then I decide [whether or not] to go to hospital.

Paul Evans: Do you get any warning when these episodes are going to come?

Khadijat Jose: Sometimes I get a warning, but sometimes I don't know that anything is going to happen – I just wake up in the morning and I'm in pain.

Dr Oliver Seyfried: Sickle cell pain comes in all sorts of formats. The common ones as we mentioned are the bones. And when a patient feels sickle cell pain they feel it in their lower back, their arms, their legs, their chest and their abdomen. The fact that it affects their lungs it doesn't tend to be painful, but it can cause all sorts of disability: pulmonary hypertension, high blood pressure in the blood circulation of the lungs is something that [also occurs]. That's not typically pain but it has serious [consequences] on how people can go and live their lives. They get short of breath up half a flight of stairs, and when you're a young person that's very limiting.

Dr Elizabeth Rhodes: Some people actually never get any pain or get very, very rare episodes of pain. Some people manage their pain, if they're moderate pains, at home, and we try and educate patients as to when that's a good thing to do and how to manage it, and to support them doing that, but also making sure they know when they should be coming into hospital if there's – you know – the pain is too severe or there's any other concerns, if there's sort of, sickle affecting lungs and things like that, or infection.

So, some people are fine, some people have every day, or chronic, pain that doesn't need an inpatient admission. So it's trying to identify what the pain is, what the triggers are, what makes it worse, as well, so we know, for example, that people who are very stressed at various times; you might have other things going on in your life that makes pain difficult to manage. When it's difficult to deal with pain, that can make the pain worse. If [you've] got a busy job or if you're looking after children, if – you know – Wednesdays are always a busy

[day], so trying to identify things like that, trying to identify if mood plays a role, how we can help with that – you know – pain makes mood difficult, mood makes pain difficult. And looking at things like relaxation techniques and distraction and all those other things that can work together, and making sure that the medication that you're taking is the right one for that situation as well, so we're trying to get sort of the best pain relief with the least amount of medicine, really.

Paul Evans: So self-management is important as in any chronic pain condition.

Dr Elizabeth Rhodes: Absolutely.

Paul Evans: They talk about, or you talk about, or we talk about the pain cycle where the condition makes you depressed or anxious – this, that, and the other – that feeds back into the pain so it's a spiral that just keeps going and going.

Dr Elizabeth Rhodes: That's definitely one role, but also the different thing, probably, with sickle cell disease is because there are these crises going on, so making sure that also you're safe and it's not affecting you in such a way that it does need a doctor and medicine in hospital.

Dr Oliver Seyfried: Part of the syndrome of sickle cell is what's called a vascular necrosis, and that's where the sickle cell blood shapes cause blockage and inflammation to the blood vessels that travel to the bone, and it causes the bone to collapse. It does occur most commonly in the hips, apart from the spleen which is an organ in the tummy, the hips are the next most commonly destroyed organ by sickle cell disease. The knees are partially affected, but to a much lesser extent, and the shoulders perhaps more than the knees but less than the hips. The vertebrae, the bones that make up the back, they also have a pretty poor blood supply and they can collapse, and you can imagine if a bone collapses it can have profound impacts on function and pain.

Paul Evans: Can that sort of damage be prevented?

Dr Oliver Seyfried: From the bone pain point of view – again, it affects different types of the disease in a different way – we know that fifty percent of people with the homozygous variant, which means they've got the serious [variation] of haemoglobin SS, at thirty five years of age fifty percent of people will have their hips severely affected by a vascular necrosis.

Can it be prevented? Well yes, if spotted and diagnosed early, there is a small place for prophylaxis, some surgical operations are available to prevent the head of the femur, the hip, from breaking down. Otherwise, you're looking at good physiotherapy, bed rest if needed, to allow, perhaps, some of the bone to regenerate a little bit. But no, prophylaxis is largely absent.

Paul Evans: Dr Oliver Seyfried of St George's Hospital London's multi-disciplinary Red Cell Pain Management team. And the term 'prophylaxis' means prevention.

Two other members of the team are clinical psychologist Dr Jenna Love and specialist physiotherapist, Rebecca McLoughlin. Rebecca first.

Rebecca McLoughlin: Within a really good multi-discipline team there's a huge amount of overlap with roles, but then there are aspects of the roles that each profession will have more expertise and more knowledge about. So a physiotherapist working in pain management might mainly focus on the impact of pain on movement and activity, and physical function, and understanding of pain mechanisms, the way that pain influences our body and our movement and our activity.

Dr Jenna Love: Where the psychologist and the team tends to focus more on the impact that pain will have on moods and emotion, might be working with people exploring particularly unhelpful thoughts that they have about pain or their condition, thinking about communication and the impact of pain on relationships and families. And I think what's really nice about Rebecca and I is that we're able to be in the same room at the same time, a lot of the time with the people that we work with. And so you'll hear that the things dovetail together really nicely. So Rebecca, for example, might be talking to somebody about increasing activity or movement, but what she'll also be doing is helping them to explore what thoughts and beliefs are getting in the way of them doing that activity. So we're very much always talking about physical and psychological in a very integrative way, so if we're able to identify what the beliefs are that stop them making that change, then we can help

them to change those beliefs to more helpful ideas. So it really is a very integrated way of working.

Paul Evans: So, for instance, just telling somebody that they need to do more exercise is ignoring the fact that it's not just the condition that might stop them doing the exercise, but it's the thought processes: "What happens if...?", "Why…?"

Rebecca McLoughlin: Yeah, yeah absolutely. And those things are always unique to the individual. So a population of people with the same condition may have very different beliefs about what that condition means in terms of their ability to move, or the consequence of movement, or the consequence of activity. So part of our role is to really unpick, for the individual, what does having this condition mean and what impact does that have on the choices you feel able to make, on the beliefs that you have, on the thoughts you have about, say, movement and activity.

Dr Jenna Love: We focus quite a lot on people with chronic pain; so thinking about, not necessarily the type of pain that might bring them into hospital with a crisis, but the kind of everyday, or regular, pain that is there a lot of the time. And often that's a sort of pain that people just struggle with at home. And that's quite an expectation, "Well you have sickle, you will have pain". Often, if people do a lot of movement they might find that that flairs up their pain significantly, so they get worried about doing movements, and think, "Oh, I better not do that because I've got to be able to pick the children up later." So they often limit movement, and then of course the impact of that is that they become, you know, lose a bit of fitness and become a little bit deconditioned, so that if they then do more activity again it can increase pain. So people can get into really unhelpful patterns with activity, very understandably, where it actually feels quite difficult to do activity and movement.

Paul Evans: You call that "the cycle of pain", don't you?

Dr Jenna Love: Yeah, quite often, or thinking – people talk about different words, so "boom and bust of activity", or…

Dr Jenna Love and Rebecca McCloughlin: "Over and underactivity"

Rebecca McCloughlin: And I think all of those patterns, as Jenna said, are very understandable; it makes sense in the short term that if something feels painful and if something has a really difficult consequence, it make sense to avoid it. But if we have a condition where lots of things aggravate pain and lots of things have an unpleasant consequence and we start avoiding them all, quality of life gets significantly reduced and then we start to hit more and more problems.

Paul Evans: The "boom and bust" that you mentioned, that's when you're feeling good, when you're feeling well, you try and do everything, and you bust.

Rebecca McCloughlin: Yeah, you pay for it.

Paul Evans: And you go further back even, sometimes.

Dr Jenna Love: Absolutely. And one of the things that we've noticed is that sometimes, because people with sickle cell have that history of regular crises, that what can happen is, again, their thoughts get in the way and they think, "Ah, pain's increasing, does this mean a crisis is coming? I better rush around, get everything done, because who knows what's going to happen. Might I end up in hospital?" So I think the "boom and bust" can even be exacerbated in sickle cell because there is that history of, perhaps, needing to be hospitalised with pain that can mean that, actually, the pressure to get things done is quite significant.

Paul Evans: How do people feel when they're told that "a psychologist is going to manage your pain"?

Dr Jenna Love: There's a psychologist also based in our service called Dr Penelope Cream, and she's been working with the sickle cell patients for about four, maybe five, years. One of the very helpful things she's done is help to normalise the sense of seeing a psychologist, and actually we've not come across as much resistance to psychology as we might have anticipated. There's always the people we don't see, of course, but I think we're very, very careful to explain that we're never referring to a psychologist because we don't

believe the person's pain, because we think that they're – it's all in their mind. We are very much of the idea that psychology is important because pain affects our thoughts and our emotions, and it can lead to a whole host of really difficult psychological conditions. It's very understandable why people with very significant ongoing pain can start to feel anxious, start to feel worried about doing things like activity, that they can start to feel low in mood, can start to feel angry, and there's a lot about sickle cell about, "why me?", and the injustice of the condition as well. So I think we help to give a clear rationale for why psychology might be involved, in that it's about helping you cope with the emotional impact of the condition and nothing to do with being seen as – in any way that they're not coping in a helpful way.

Paul Evans: I suppose a lot of that is down to education as well. I mean, getting people to understand that pain is a biopsychosocial thing.

Rebecca McCloughlin: Yeah, and I think that's one of the really important reasons why we work within a multidisciplinary team, and that we work mainly in the outpatient setting, but that our team spreads across inpatient and outpatient settings. And that some of that education comes – kind of filters down from all sources and it's really about trying to help people to see a very physical condition like sickle cell that's often traditionally been treated very medically isn't just going to have a medical, physical impact; it is going to have that broader impact. And our consultants like Dr Rhodes do a huge amount in terms of helping to educate patients about the broader impact of pain and hooking them in to more biopsychosocial founded interventions.

Paul Evans: That's clinical psychologist Dr Jenna Love. Dr Elizabeth Rhodes again.

Dr Elizabeth Rhodes: What we should be doing in the UK is identifying all children born with sickle cell disease or sickle cell anaemia before they're born, actually. So we've managed to educate the parents who are at risk and then making sure we make that diagnosis at birth. So from the very beginning you know that you get to meet your sickle cell team and you get to see your paediatric haematologist, so the haematology doctor that's going to be looking after your child, you know, at sort of three months of age, and so we start that education process right at the very beginning. And then it's really key to remember to do that as that child gets older, so as they take on their own condition, and as they come into

adulthood that we don't just assume that it's all remembered from when their parents were told.

We run workshops where we educate patients on their disease but also on their pain and different types of self-management and hospital management as well.

Paul Evans: For somebody who's just found that they have sickle cell disease, what advice would you give?

Dr Elizabeth Rhodes: One important thing is to make sure that you are known to a specialist centre that looks after – so, you know, either via either the GP or something like that, to get yourself referred to the hospital. That doesn't mean you have to spend all your time in hospital, but it's important that we see you as an outpatient as well, so we try and see patients at least once a year, some patients need more, and then we can make sure that all the complications are being looked for and managed. And therefore, you also get into the system where we've got the nursing support and psychology support and everything else you needed if you need it. So trying to make sure that you're in with a hospital team that's looking after sickle cell disease is really important cause they'll have the access to the other support systems that you'll need as well.

Paul Evans: So I guess in that it's a genetic illness, there's a good start for you that you know who will get or who might get it.

Dr Elizabeth Rhodes: Yes

Paul Evans: And getting that help into the family in one generation might pass all the way through.

Dr Elizabeth Rhodes: Yes. So it's picking up who's a carrier, because people who are carriers usually have no symptoms, so it's trying to make sure we identify those people who are carriers so that – and we usually do that in pregnancy so then they know that they're at risk of having a baby who might be affected. And then once we know that that child's affected, throughout their life we will talk about partner testing and genetics as well.

Khadijat Jose: For me being not just a carrier but I have sickle cell disease, it affects my relationships a lot, because it's not just about meeting and liking someone, I have to ask, "What's your genotype?", because you can't be a carrier, you have to be someone who doesn't have the sickly genotype at all.

Paul Evans: Khadijat Jose. I mentioned at the start of this programme that exact figures for the instance of sickle cell disease were hard to come by. Does this mean that there's been a lack of interest or awareness by the medical profession, or indeed by society itself?

Dr Oliver Seyfried.

Dr Oliver Seyfried: The life expectancy of sickle cell disease in the early part of last century was teens; if you survived infancy, you were lucky to make young adulthood. We now, through medical and social advances – longevity is almost normalised, so we can now concentrate on how we manage this. There's another side of it, I think, that people expect sickle cell disease to come with pain. And so you say to your patient, "You've got sickle cell disease, are you in pain?", they say, "Yes", you go, "Right you are"; it's almost expected that people live with it, and I think maybe that's the attitude that's changing. Don't also forget that, rightly or wrongly, people in this country, in the United Kingdom, with sickle cell disease, either black or from the Indian subcontinent are part of an ethnic minority and with that comes all sort of social issues that, I hope, are starting to dispel, but may have suffered at the hands of being an ethnic minority and all that comes with that.

Paul Evans: So, it's education to the communities themselves, to the potential patients, to the carriers.

Dr Oliver Seyfried: Absolutely. I meet many patients who could be carriers of the disease, and you ask them, "Do you have sickle cell disease or sickle cell trait?", and they look at you blankly. It's got to be spread; people have to know, I think on a general level, especially in the black and Indian subcontinent community about the thalassemias as well. This is another type of haemoglobin disorder that's important, that can create pain. They've got to be aware because it does affect them and their family if their unlucky; if two people with sickle cell trait meet, have a child, one in four of those children will have this serious version of sickle cell disease. And NHS England are running the sickle cell and beta thalassemia programme with a view to getting people prior to conception, through pregnancy, and in to get early diagnosis

in there because early diagnosis might lead to earlier intervention, and a healthier person throughout their life.

Paul Evans: Dr Oliver Seyfried, consultant anaesthetist at St. George's hospital, London. He mentioned the national sickle cell screening programme in the UK. Dr Elizabeth Rhodes again.

Dr Elizabeth Rhodes: If you're in an area of high prevalence, so for example if you're pregnant in central London, we'll test all women, and then if you're affected we'll offer to test the father of the baby. If you're in an area of low prevalence, so perhaps where sickle cell isn't as very common, we do a family origin questionnaire and we look at your full blood count; so to look to see if you're anaemic, and if there's some suggestion that you might need screening we'll screen you then as well. So we should be trying to pick up everyone in pregnancy.

Paul Evans: Are there specialist centres throughout the UK?

Dr Elizabeth Rhodes: Yeah. Throughout the UK but not in, sort of, absolutely every area, so again the areas of low prevalence may not have a specialist centre, but they should be able to link to a specialist centre. There are several in London, Manchester, and Birmingham.

Paul Evans: Dr Elizabeth Rhodes, consultant Haematologist at St George's in London.

You can find more information about sickle cell disease at the Sickle Cell Society website, and the address is http://sicklecellsociety.org

I'll just remind you that whilst we in Pain Concern believe the information and opinions on Airing Pain are accurate and sound based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf. Don't forget that you can download all editions and transcripts of Airing Pain from Pain Concern's website which is www.painconcern.org.uk . There you'll find information and support for those of us with chronic pain, our families and

carers, and for healthcare professionals. There's also information on how to order Pain Concern's magazine, Pain Matters.

Last words to Khadijat Jose.

Khadijat Jose: You don't want to meet someone and then, you know, you are hitting it off and next thing you're asking, "what's your genotype?", it's kind of weird. But it's something that has to be done.

Paul Evans: And, pardon me if I'm prying, have you done that with people?

Khadijat Jose: Oh my god, several times. All my boyfriends I've asked, "what's your genotype?", and to be honest I think that has been a good thing for me cause I have a son now, and maybe if I didn't ask or we didn't do tests then I would have a son who is having the sickle cell disease just like me. Because if I marry someone who's a carrier then my child has a seventy five percent probability of being someone with a sickle cell disease, and I don't want to have to put my child through what I'm going through. I want a child that will be healthy and happy to do whatever he wants to do, whenever he wants to – everything. So yeah, it's quite important you ask those questions.

Paul Evans: So is your son a carrier?

Khadijat Jose: My son is a carrier. All my children are going to be carriers.

Paul Evans: But he doesn't have sickle cell disease.

Khadijat Jose: But he doesn't have sickle cell disease. So he's just a carrier.

Paul Evans: So you'll be passing that information on to him.

Khadijat Jose: Yes.

Paul Evans: And that affects the whole of his life to come as well.

Khadijat Jose: Yes, that does. It's quite important that we all educate ourselves on this issue. If you have sickle cell disease or you're just a carrier, it's important that they know and when they're dealing with their life issues, relationships, that they also ask those questions, because it would be nice if a lot more people knew about this condition, and then that way, maybe, there'll be a little more empathy as well.

Paul Evans: Empathy not sympathy?

Khadijat Jose: Empathy.

Contributors

- Dr Elizabeth Rhodes, consultant haematologist at St. George's Hospital in London
- Khadijat Jose, PhD student at Cardiff University
- Dr Oliver Seyfried, consultant in pain medicine and anaesthesia at St. George's Hospital in London
- Dr Jenna Love, clinical psychologist at St George's Hospital in London
- Rebecca McLoughlin, specialist physiotherapist at St George's Hospital in London

More information
*For more information about Sickle Cell disease visit the Sickle Cell Society website: http://sicklecellsociety.org
*For more information on the National Sickle Cell Screening Programme and parent education in England visit : https://phescreening.blog.gov.uk/category/sct/

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