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| ***Welcome to the interview today. I just wondered if you could start off by telling me a little about the condition you have in your family.***  Well my condition is either called [**sickle cell anaemia**](http://www.tellingstories.nhs.uk/glossary.asp?title=sickle%20cell%20anaemia) or [**sickle cell disease**](http://www.tellingstories.nhs.uk/glossary.asp?title=sickle%20cell%20disease). I have suffered from that since the age of two. I have one other sibling who suffers from the disease which is my sister. Basically that’s it really.  ***What are the main symptoms of the disease that you experience on a day-to-day basis?***  Throughout the years, I have had so many different symptoms. I have been paralyzed, partially blind, loads of other. But the most common one is pain, so I get a lot of joint pain, arms legs and so on.  ***And how has this changed and affected your life?***  I didn’t have much of a school life. I spent most of my time in hospital. They put it down to every time I used to get excited, they would put it down to that. It used to bring on attacks then or the cold weather so I spent a lot of time up until I was about 14. Probably about 12 or 13. I suffered really, really badly and then it seemed to stop at the age of 13. And then up until I was about 16 it came back again, but not as severe as it was when I was a child. Then I had a really severe attack when I was 18. I spent quite a lot of time in hospital then. I had [**spleen**](http://www.tellingstories.nhs.uk/glossary.asp?title=spleen) damage then. They think I had a ruptured **[spleen](http://www.tellingstories.nhs.uk/glossary.asp?title=spleen)**because I used to do martial arts so they thought that’s what caused all the rest of it so I was in hospital quite a while. I lost about 4 stone in weight. That was one of the worst things was the weight loss because you could see all my bones and everything else like that.  ***Did you get much*** ***[genetic](http://www.tellingstories.nhs.uk/glossary.asp?title=genetic)information from the NHS staff like the nurses?***  No I never got any information about that at all. Basically when I was in hospital, I was like a guinea pig. They used to give me tablets and stuff like that and see if it would work and you know all kinds of stuff. I was on quite a lot of medication then but I was not on medication at home. All I used to take at home was folic acid so they never really knew about it only when I was in hospital. Apparently they used to give me different medication but it was quite a lot you know for somebody of my age.  ***When you’ve been in hospital what kind of experience have you had from the different nurses and the different doctors?***  What stage when I was younger are you talking about?  ***Well throughout really.***  Well when I was younger and I was a kid I was on a children’s ward, so it wasn’t too bad because obviously there was only one children’s ward I went to and it was just the same I mean like I said, they just used to treat us like for different things. Just used to take pills after pills after pills and stuff like that and never really told me what the pills were. I mean I didn’t really find out much about it actually until I was about 21 years old when a lady came around and explained to me what would happen in the future and all that kind of stuff. That shocked me. It really did because I just thought I would grow out of it because my Mum didn’t know and like I said I’ve got a younger sister and I could always remember saying that day she cried. She really really cried. It always stuck in my mind because the lady said like it would be hard for her to have children and stuff like that and like I said our life expectancy at that time well, was quite low. I was basically gutted. Absolutely gutted. And I can just always remember that day with my sister crying. Devastating news. Devastating news. Just something inside seemed to have snapped basically. Couldn’t believe it. Couldn’t believe it.  ***This lady, was she a*** [***genetics***](http://www.tellingstories.nhs.uk/glossary.asp?title=genetics) ***expert?***  Yes she knew more about it, she started a programme. I can’t remember her name to be honest with you. She came round to the house. She introduced herself. I said something like that. We asked a load of questions, what do you do and stuff like that. She was basically an expert on it like she thought she knew at the time and she started telling us all sorts of things about people dying. I never thought I was going to die of it or anything like that. And what could happen and basically if you did certain things or if certain things happened to us like say we got a really bad chest infection we could die and stuff like that and if we had food poisoning we could die like you know it was all stuff like that. Very very frightening. Even as a 21 year old like that really did scare me.  ***Looking back on that experience was that a useful experience or was it one that you wish you hadn’t had?***  I have reservations about both really. I mean sometimes nobody wants to hear bad news. But at the end of the day like she was honest. I look back on it now and I think about it still. Why wasn’t I told about it before? That’s what I think the difficulty was. If I was told before maybe I could adjust and after when the lady told me, I went way off the rails. Used to get in trouble with the police and all sorts of stuff like that. Used to try and drink myself, like I said I was an alcoholic for quite a long time. I just used to drink myself basically into a stupor and stuff like that. Really really bad. Because that was my way of dealing with it. I suppose my way of dealing with it. Lost my job through it. All sorts. It was a really really bad time. Really bad time.  ***After that happened did you get any support from this specialist or anybody else to come to terms with it?***  No. No. I had to basically deal with that by myself. Me and my sister had to face the family. There was a lady called who we talked to quite a lot and she was quite good and that’s how I got introduced into the Sickle Cell society basically and she gave me more information a bit more positive than the other woman. I say positive. It was a lot easier to talk to her and for her to talk to us. So gradually I accepted it quite a lot more. It never really got any easier because I remember on two occasions I almost died. My liver started to fail. That was one of the worst ones. I was about 24. I can remember waking up. I was so, I was really really cold and it was in summer. I was really really cold and the doctor came around and I mean I had 2 and 3 quilts on top of me and I had a temperature of 110 and it was rising so I was rushed into hospital and had a liver **[biopsy](http://www.tellingstories.nhs.uk/glossary.asp?title=biopsy)**and said my liver was dying and I thought basically that was it for me. I accepted it in a way. It was like when they were saying to us our life expectancy of people I can remember people who were dying when I was 27/28. I only expected to live to 28 anyway so I thought I’d live life to the full really. To have suffered a liver, that was quite bad.  ***What’s your experience been of the NHS care you’ve received in terms of good experiences and bad experiences?***  When I moved over to the adult wards I found the staff had no knowledge of it at all really hardly any of them. But some of the younger ones were quite sympathetic. The older ones weren’t but some of them were quite sympathetic. I had quite a good rapport with some of them but like I said it didn’t help that I kept going to different wards but once I knew and I kept seeing her over and over again it wasn’t too bad. It was just the amount of drugs I had to take just to get better and they couldn’t believe it cos like I said I mean you know they couldn’t believe how much I had to take just to get well. Because there’s quite a lot I can remember at one stage I was on 350 mgs Pethedine every hour which is astonishing basically and it wasn’t too bad.  I didn’t like going in to hospital but it wasn’t too bad. We had this dedicated ward where we could go and by-pass the A & E I mean that was brilliant then. Absolutely brilliant. For a while I wouldn’t go and see a doctor. I wouldn’t see a consultant because at the end of the day they couldn’t cure me so I thought what’s the point of me to keep going back. And I remember being ill for 4 years, constant pain all the time but I wouldn’t go into hospital. Like I said after that last experience I would not go into hospital and I thought I would rather die at home. Until we got that dedicated ward and I thought well I’ll give it a try and the staff were really good, knowledgeable and stuff like that and you know it was great. It was the first time I felt safe and comfortable basically. And that’s all changed again.  Because the last experience I had was last October where they never had no beds. They closed down a lot of the beds on this ward where we were at and we couldn’t get onto the unit so we were shifted around twice and like I said I was in hospital and I just wanted to cry really. Because the ward they put me on the staff didn’t know anything about it. Not a bit. I had to argue with one staff who gave me paracetamols and said that is to accentuate the drug and I thought he thinks I must be stupid. If he thinks I could take paracetamols at home and like I said I had to argue literally argue. And basically the reason what it was they only had 2 trained staff and you need two trained staff to issue the drug which was diamorphine, so if one of them went on to dinner, basically this was in the evening, so if one of them went to their break in the evening I had to wait then. Like I’m in pain so it’s not getting any better I had to wait and wait. That’s one of the worst experiences I have ever had and to me the most frightening. Like I said now I’m scared of going back into hospital.  ***If there was one or two messages you wanted to give us to improve the care of somebody like yourself with*** [***sickle cell anaemia***](http://www.tellingstories.nhs.uk/glossary.asp?title=sickle%20cell%20anaemia) ***and your family, what would those be? What would you want to see improved? What would have helped you when you were younger and what would help you and your family now?***  I would say more support when I’m at home and to be able to get onto the actual ward that was chosen for us and then we could feel a lot safer. But the main thing is support at home because as soon as you are out of hospital you get nothing.  ***What would that support be like for you? In what form?***  Basically more care, somebody to ask how I am and to talk to. If I’ve got any problems, somebody that I can liaise with. Somebody who understands basically because unless you’ve got it, I don’t think anybody understands. You can’t live with the magnitude of where you wake up every single day of your life in pain. And you try to explain to somebody and I look quite fit and healthy to be honest with you but like I said trying to explain to somebody like a normal person that you’re not fit and healthy is mind boggling basically. It’s hard to get through to somebody who doesn’t know who hasn’t lived with it or hasn’t lived with somebody who has got it. It’s hard to understand I think and that is why I want somebody who understands and somebody who can actually support me. I’ve got my family and my wife and she is not a nurse. We’ve got kids. She can’t look after me. I don’t want her to look after me. It’s not her job. I would want somebody who basically wants to look after me and care for me. Don’t get me wrong my wife does care for me and look after me but I want somebody who knows, who has a certain knowledge about it and can respect what I say and believe what I say because that’s another thing.  A lot of staff when you go into these different wards, they don’t believe you. They just don’t believe you. They say well you can’t be in that much pain. They actually think you want to be there. I mean I don’t want to go into hospital. They think you want to be there Nobody wants to go into hospital. So I’m not going to make up stories that I am in that much pain just to get . . . It don’t make sense. Like a drug addict do you know what I mean. It doesn’t make sense to what they say. Do you know what I mean? And that’s what’s hard for me. I would rather somebody explain to that staff member who has no knowledge of it to explain to them this is what’s going on rather than me getting agitated and angry and explain it to that person. So I think more educational knowledge of what’s going on and staff need to be told basically. It’s not going to get through to everybody but everybody understands what cancer is. It’s along those lines. I mean the pain like I said is horrific.  ***Just to go back to that point about needing somebody to talk to, did you ever get any support like that?***  No.  ***Do you think if you had somebody who was able to do that, that would help you?***  That would have helped me when I was younger. It would really have helped when I was younger because when I was younger nothing was any good. Nothing anyone told me. And I thought I’m not going to live very long anyway so if somebody had told me be positive, you can live a full and happy life, that would have been a lot better and I would have been more grateful. But now that’s what gets me. A lot of people still don’t understand. That’s the main thing that gets me. They still do not understand in this day and age. And they don’t believe you. Unless you’ve dealt with that patient constantly nobody believes that you can be in that much pain.  ***Is there anything else you would like to share about the project that we are doing that you think we need to think about or just generally about the experience you have had?***  Well I think the main thing is as long as you are listening with an open mind and you just take time to think about it and just try and read up on it or just to get some sort of foresight on it you know that’s all I want. As long as you get some sort of educational understanding about it that would please me. |

**Discussion Forum Questions. Remember to have a professional nursing reference for all discussion forum assignments.**

**1. Tony talks about how the lady came round and talked to him and his sister. In your opinion, was this done appropriately? Are there any issues around ethical practice that arise from this action? How could the information have been given to Tony and his sister differently?**

**2. If you have contact with patients with sickle cell disease, what has been your experience of pain management? Reflect on ways in which it may be possible to improve pain management in your own practice?**

**3. How could this story change your current practice?**

**4. Do you think that this could happen in a hospital in the United States today or do you think that the nursing staff is educated on the this genetic disorder (Sickle Cell Disease) and therefore, educates their patents and families?**

on post 7