

Deborah Awino

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PARTICIPANT: Originally I come from Kenya and I was born in a small village called Yala [sp?]. That is where I grew up and I came to the UK in 2001. I came as a visiting visa but at some point I got stuck in the middle and when you are stuck you have no way you can move forward so that's my story. Come 2006, I fell sick, I didn't know what was happening. I went to my GP and my GP told me, oh you'll be fine, just take co-codomol. At home I took co-codomol. In the morning it was a Sunday, my children used to come and visit me every Sunday because they like something called pancake, so I normally wake up in the morning, cook for them, I have [missed] here. I cook for them and then they come in the afternoon after church to pick them up. So after finishing cooking my chapatti, as in my normal routine on a Sunday I went to church, came back and I slept on the sofa with my jacket on. I was shivering, I was cold, I had the heating on full. So I decided to leave my door open just in case they come and I don't hear. So they came and they opened the door and they found me. I couldn't hear them. I heard sound from very far. Mum is not feeling well. Look, the heating is on and she's sweating and she's fast asleep. I could hear that sound from far and then one of them shook my hand and said Mum, what's happening? I said, oh, I'm fine. Then what she said first was, no no no, we are going to Accident and Emergency. So she went to my bedroom, took some few clothes, took me to MRI.

So when we reached there, there was a doctor who came and took me to examination room. I had some patches, patches, patches all over me. I didn't know because my temperature was high but I did not know what was going on. So the doctor said, Christina, you can take your mum home, she's fine. So my daughter asked, are you sure my mother is fine the way she is? The doctor said, yeah, she can continue taking what she's taking, what she was given from the GP and then she will be fine. So I went to my daughter's place, I didn't go to my place.

Come Monday morning around eight o'clock I was coming down to go and have my breakfast. I get a call [...]. Can you come to MRI immediately? Then I asked myself, I was there yesterday, now what's the problem? So she said, I'm sending an ambulance. Then I said no, I have someone who can drive me. We are giving you half an hour to be at MRI. So to me I thought I was already dead.

So we went to MRI with my daughter, she drove me there. I was taken to a small room and I think five doctors came in the room. Every person was touching my legs, touching my heart, taking my pulse, I don't know. So all the patches were on me. After that a lady doctor came and looked at my daughter. She asked my daughter, why did you take your mother home last night? And my daughter said, the doctor who who was looking after her said she was fine, she could go home. Then that doctor just told my daughter, you are very lucky to have your mother alive now. We are admitting her. So I was admitted at MRI, I think on the 17th of January. From there my fever grew then went down, it was just trying to control it. Nothing. The doctors came in and out, came in and out. After a while another doctor came and said, do you mind if we test you on HIV?

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PARTICIPANT [continued]: But being I was so desperate I was very poorly, I said I don't mind. So they took the blood and in the morning she came and she started telling me, you know, I want to tell you something but I don't want you to overreact. I said what is it? She took a pause and looked at me, then looked at the other side. You are positive. It didn't ring a bell, what is positive, what it means. So I asked her, what do you mean positive? You are HIV positive. And then what I saw was death. Was death. So after that, she held my hand because I was going to go to the bathroom and take a bedsheet because in Africa, being HIV positive you are dead or you are somebody who is a prostitute.

So I was considering myself, how am I going to look to my children? So she said, I'll be with you here until somebody else comes. So she was with me for about four or five hours, trying to talk to me. I was just numb. Then another doctor came and said Jane, it's never the end of the world. You are in the right place, you'll get proper treatment and be ready to be in the hospital for a whole two months because you are CU4 is ten. So I said okay, I don't mind. So my daughter came and I won't tell her what I was told because what she will think is my mum is dying now. So I just told her, oh, I've got, because it was TB, pelvic TB, and I was not coughing, but there was a TB. So I told her they have diagnosed me with TB. That's what I told her.

So I was there for two months, when I was discharged I started going to the clinic and my viral load was it was high, over one thousand and something. So I kept on going to the clinic but the MRI nurses were good. But later on there were some doctors who started asking me, how did you get HIV? And I told them, nobody knows how this thing comes about. If you could tell me somebody who was suffering from cancer I would tell you how somebody gets HIV, because me, I don't know. Then I started to cry and she started consoling me and I was very very weak because I used to go to the hospital almost every day with my daughter. I can't walk two steps because my breath was... so as it goes, I started seeing treatment was like, I was not coping, because HIV and TB together, they had to stop one because I developed jaundice because these drugs, I was taking about fifteen tablets in a day. So they had to stop another one so that they could clear off the other one. So I stopped the HIV one for six months because they were treating TB. In the process I developed DVT, blood clot on the legs.

So it was a series of problems in me but at some point the TB was under control so they took me back, I was put back on retroviral. The one they gave me I was resisting because the CU4 was just going high loads, so they changed again. I went through about six changes since I was diagnosed. But going back to what I've experienced with HIV, you have to choose your friends, because even now, my children doesn't know. They don't know because I don't know how they would react to me.

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PARTICIPANT [continued]: You have to choose your friends, the ones you have to talk to. You have to limit your friends. Sometimes it forces you to isolate yourself and being that you are isolating yourself it triggers so many other things in your head. If I

die, better for me to die, because if I cannot interact with my friends the way I used to be, then I am nobody. Why should I live? But some doctors can tell you, they can refer you to counselling. But after the counselling, because they do it after six months, you stop, you go back to the same thing, because you have friends limited, you have your movement limited. When it comes to testing sometimes when you go for blood test, the doctor who asks you to go for blood tests, some of the nurses will always put you down, for instance I went for full blood count, but that's slip was written HIV underneath it. So the nurse who took this slip went to the other nurse and she's showed her, and instead of talking to me, that woman screamed and said, oh my god! We have to close the lab immediately. So I said to myself, what is wrong? Is it because that paper is written HIV? And when you are going through a lot I just grabbed that paper and I said, you know what, you must have yourself tested first before you scream to close the lab. So I went back to my GP. I told him what has happened to me because I said you are not going to test me, I am going back to the GP. So when I went back the GP called that nurse but I think that nurse was taken away from the blood because I have never seen her there again. So some of the nurses also mistreat us in a way that Africans are the ones that are having HIV most, that is how they consider us. To them themselves, they are not been tested, they don't know how that thing affects the body because it's, like, it damages the whole body, you are walking but you are walking with a death certificate. Now my bones are, they can't hold my body, my bones are cracking. I'm put on bone tablets. It develops so many things. Sometimes you get, a few of my friends, they've got brain tumours. So when somebody tells you oh my god, you are HIV positive, you feel like, this person is undermining me and herself, she doesn't know. Come to the doctors. The doctors, some of them will always tell you when you are complaining something, they will tell you, oh it is because of your HIV. They will always put the blame on the HIV. Whether you are complaining of chest infection, it's HIV. So you don't know where you stand, that's why you just have to be on your own, move on, and do what you can do. But at some point if you remember what you used to do and now you cannot do, you have to limit your friends, you can't even, when you have a boyfriend or a man friend, or whatever, whenever you tell them you have HIV they run away, they just don't talk to you. So it becomes so difficult with those people who are living with HIV, it's a terrible scenario but how to campaign, for instance we went to campaign in church so that it can be something which everybody knows. The pastor said, if you are telling me that we talk this thing in church it's like you are telling me to preach sex in church.

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PARTICIPANT [continued]: So to him, HIV is transmitted only in sex. He doesn't know that this thing you can get through injection, you can get from blood transfusion, so they don't know that. So the pastor just put us off. So when you are alone, you are alone even in church. They now preach, sing, if you know you are having any sickness, could you please stand up and they will pray for you? They know you are there but they are shouting because if you don't stand, we know you will die. So when you are death, it's like everyone is pointing at you, is aiming at you. So even the church leaders are not very good for us. Very few people now, you find you don't even want to go to church because once, you keep on changing but if you are seen somewhere, now the HIV lady has gone to the other site. So it is like, stamped on your face, stamped on your address, moving with it. So it's a terrible

disease. Very terrible. Coming to life you cannot have your full life like you used to have, coming to friends you have no friends, I can only make friends with HIV people because if I tell somebody that person will go and tell another one and another one. You have to choose who to tell. So it becomes so, we can't campaign about it, because if you campaign about it, it's like you want to spread the word of sex and it's not only sex with brings HIV and it is affecting you emotionally, you are disabled, you can't move. Not disabled physically, but disabled emotionally, mentally, you can't do anything. You can't move at all. You can't move at all so it is a disease which is, I don't know how we can campaign about it so that it can reach out to people but this thing is not a killer, you can live with it much longer than even cancer, but it is feared more than even cancer. Once you have HIV you are finished but if you have cancer it is just normal. So I think it is very difficult to us to live with it.

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INTERVIEWER: You mentioned friends and lack of support. I was wondering if you could say a little bit about the organisations which you've gone to and been involved with and worked with because obviously I met you at black health agency for equality. Could you say something about your involvement with BHA or GHT or these organisations?

PARTICIPANT: Yeah, when I was in the hospital first I was introduced to GHT and I got a lot of support there. The people there were encouraging me, when you were there you don't know the people you are going to meet. So when I was told, some of them they look very healthy, they look very well, so I said I was very thin by then and I was very scared but in that support I got motivated that I am not alone, so it made me feel like I am wanted somewhere but before that I couldn't even come out of the house because from the hospital everyone knows so and so is HIV. And again when I joined BHA, coming back to volunteering, there are always very supportive because the chief exec would always find a way of getting women together and socialising and talking about difficulties they're going through so you ease your attention and I find BHA very very supportive coming to HIV part of it. George House are going down, they say they don't have funding but they still support us in a way but I stopped volunteering there because I couldn't volunteer at BHA at the same time volunteer there but I find the organisations very supportive.

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INTERVIEWER: Could you say a little bit more about your volunteering and the kinds of people you meet through volunteering and the kinds of advice that you give?

PARTICIPANT: Yeah. Through volunteering, before I started volunteering with BHA I was doing one to one with GHT supporting the newly diagnosed because I think I was in volunteering you gather experience and when I joined BHA it enhanced my volunteer label because people find they are from GHT like black minority. They find me there, we sit, I tell them my story, they tell me their story and I always tell them, look here, you have to move on, you accept it to be your problem so that you don't hand it over to anybody else. Once you want to hand it over to somebody else is when it will put you down but when you say it's my problem even if somebody looks at me I'm not going to be bothered because my body is mine, I'm carrying my body,

come medication it's mine. I'm not giving somebody else so they become relaxed and find they've got support somewhere. They keep on coming and we give them food parcel and we become friends and when they get somebody and again they say you know what, there is somebody we will take you, a place we can get support so they keep on coming. We support them when it is not our role we call Priscilla to give them some support here because there comes a point that there's some areas you cannot assess somebody but you can support someone so we call Priscilla to support them to know these paths have been identified so they come and we also give our own as volunteers and they become very comfortable and they open up as well. When somebody leaves the place you see their smiling face. When they come it's I'm finished, what kind of person am I going to meet. But after talking, seeing their smiling face, I tell them, look, I've been with it for the last over ten years. What? yeah, true. So they leave and they're comfortable.

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INTERVIEWER: Okay, I'm just going to, I think I put this microphone a little bit close to you.

PARTICIPANT: So my experience with the HIV I think nurses need to be trained and also doctors need to come and address people because some people they think even if I use a comb to comb my hair and I give it to you you'll get HIV so to some point if I was to say, if some funding can be found for nurses especially they need to be trained and also the GPs, there are some areas which they cannot do, but if you go to a GP they will always tell you go to your consultant. So you are always in between. So you go to your consultant and they say those ones you have to tell your GP. So you keep to yourself, let me stay, so we don't know what to do. So we should train the GPs as well, the GPs should know what their role is and also the consultant because maybe the consultant is specialised in HIV type medicine. Fine, but if you tell them, okay, I am suffering from this, go and tell your GP, your GP will say, that one, I think it is better if you tell your consultant. To me, I would urge if there is some funding, just a little bit, not much, we could get a few nurses from MRI, because you can find the nurse or a doctor when you are waiting at the reception, they come to call you, oh, Jane, HIV. At the reception and people are there. It is like exposing that you are HIV. So it is so embarrassing, I think they need to know there are barriers and boundaries. You don't need to expose. If I want to expose I would do it myself, I can even write an ad saying I have HIV but you are a professional, you know what you need to do, I am coming to see you, is there any need to call me at the reception and put that word again? Doesn't make any sense to me.

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INTERVIEWER: I wanted to ask Sarah to ask if she wanted to finish and maybe that's your message, I don't know. But is there anything else you want to add or are you happy to finish there?

PARTICIPANT: What I can add is frustration you get in your life, you are frustrated so much mentally, emotionally, physically, because you are like a dead walking body. You are moving but every part of your body is aching because the medication we are taking, the side effects are so, even if you say you are suffering from this

now, I have neuropathy, I don't know how it came but now if I tell my GP it's the medication of GP, it's the medication of HIV, if I tell my consultant it's because you're suffering DVT, so you have to live with it, it's a very difficult life.

[00:27:38] End of transcript.