

## Judith

[00:00:00]

**PARTICIPANT:** Originally I am from Kenya, I married and Italian, now I am separated. I came to Manchester 2013, last five years here. [missed] [00:00:16].

[00:00:19]

**INTERVIEWER:** How do you...

**PARTICIPANT:** Actually I came here to study, to do Beauty Therapy. That was 2013, but I started 2014. And the [missed] [00:00:30] is when I started to have a cough, a chest infection. I was treated for a chest infection, then I went back to Italy for... I used to be up and down, going back to Italy, so when I was there they just said I was having an infection. So I was treated and then I came back 2014, February, I think 15th. I was so ill I was taken, I went to Salford Hospital. I was not feeling well, so they were doing tests and they found loads of [missed] [00:01:10] blood clots and I was having to be... because they asked if I was ever tested for HIV. I did it back home but I've not done it in Europe, so I told them 'no', so they were forcing me to do it. I was in a bad condition, so they told me they cannot treat me, I have to be tested first. So I told them 'this is not something you can just tell someone to be tested like that', and I am just by myself in the hospital. So I called, I'll say it's my ex-husband, I called my ex-husband and told him about it, he told me they cannot force you, they [missed] [00:01:55] by the law.

If you don't feel like, because this is not easy to digest, if you're told you're sick. So he told me 'if they can read, I'm coming over so they can do it' but the way they were telling 'we can't do anything, we will just leave you like that', so I just had to accept it.

That's how. And the bad thing is, they never told me my status. Yes. Because I was having difficulty breathing and I was in a cardiology ward, so when I was there is when I think the results came. So one of the nurses, when I was in the room, because I slept the whole day I overheard the nurses saying... no, I asked for a commode and she was like, she brought me the commode, she gave it to me but she took the [missed] [00:02:56], the lid, and she put it on my bed. So I used it, then she took it back.

So in the middle of the night I was not asleep, I was awake. They thought I was asleep, because my room was next to the front office, the reception there. So I could hear what they were saying, so the nurse said 'I'm scared to touch Julie, she's HIV', so that's how I knew my status, you see. So felt, I was shocked. I didn't know what to expect. So they started to talk ill about me, so when she came in I told her 'listen, the walls have ears. What you say the walls can hear. If you're doing a job, you don't have to do the job because of money. Do something because you like it'. So that's why I have this stigma, everything started.

So they gang up against me. She went and told the other nurse 'she heard what you said'. That nurse, she started to speak in Swahili, she didn't know I am originally from Kenya, I speak Swahili and understand in Italian. Because when I was taken to

that ward my nurse was [missed] [00:04:17]. The day before she was really nice to me, I could see her giving the other nurse my details. She went to Facebook, she logged in and my name came out. One of my mutual friends was a friend. So she went and told that lady that I've come to Manchester to spread HIV. So they were saying they'd teach me a lesson, so I told the lady 'I'm really ashamed of you people, you're professional and what you're doing is not right. I work as a support and I know what it's like to treat someone bad, and the same thing, I came here and I expected to be treated by you people nicely but what... I am really shocked, this is Europe. I can expect it in Africa. Like that, talking over there... whilst she said that, I could understand what she said. She said I'm going to poo and I'm going to die in Swahili. So when you talk about people, you have to know some people, they understand another language. Watch out how you're talking.'

[00:05:27]

So I think it's great [missed] [00:05:29] because I faced them, so they decided to treat me badly, and when my cousin came he could see what was happening. My cousin had to face the consultant. Instead of the consultant doing anything instead he was protecting them. So my cousin asked: 'let's be honest, she's sick and you never told her about her status and you never even prepared her psychology, we don't know what she's thinking, and the worst thing is your staff are treating her bad and you're trying to tell me you're protecting your staff. Who is vulnerable here? Between her and your staff'. He didn't say anything. So my cousin was tight [?] because at that time he was an asylum seeker, he didn't have power, so he was hopeless.

Then the same day, my friend, she was my classmate in college, she came... because already everybody knew, Kenyan community knew, they sent my pictures around telling people that I've come to spread it. Even when I was telling my ex-husband he said 'oh, you're in shock, you're just talking because you're traumatised'. I told him 'I'm not. Even if I am, I still have my sense. I know what is going on. And I really feel bad, I never expected it to happen to me.'

So when my friend came she asked me, I told her... she asked me the same question, 'what's up?' [?] and I told her 'this lady, when she brought the commode...' everything. She asked me three times, and then I told her. She went to the reception, she told her. The lady is saying 'she's mental'. 'She's not mental, because I have asked her three times, she's repeated the same thing. Because the way I am seeing the attitude towards her, she's having the same clothes she had before and it has blood... so where the problem is, is lying between your staff and I am really shamed of you people, the way you're doing it.'

The new generation, HIV's not a big generation like before. So she called the police. Police said they could not do anything because they're inside the hospital. So they gave us a number, so these senior doctors came down... they came down, they apologised, they told me they would follow the story of what happened. So I requested my friend to sleep there because I told them I don't feel safe with what was happening. She spent the night with me there, because my ex-husband was coming the following day. He got lost because it was his first time coming to

England. So by the time he got to the hospital, because I was meant to be transferred to North Manchester, because I was having...

Because they were changing the medication [?], one thing. It was reacting with me, so it was like, they wanted it to look... I was the one... was increase it, but I was not. So the following day my friend left, so I was there by myself. So, speaking of the medicine they gave me [?], even I had haemorrhoids [?] because it's reacted with me, so even I was doing like this. So when my ex-husband came I told him what was happening. He didn't want to believe me, he was like 'oh, you are scared, you're scared of things'. So the following day, because he slept there, they [missed] [00:09:11] she was there, she was in charge, it was one of the... I can't remember because it was 2014 but she was called [missed] [00:09:21], she was the one who was following the case. So she said she was going to look for a way for me to be taken to North Manchester.

So they said I had a fever, there was no way they could transfer me, I should wait. So in the morning when I was sleeping, when I woke up... they never used to give me food, so my cousin was the one who was bringing food. So they refused to give me food. And my ex-husband asked 'why are you not giving her food?' They said 'oh, someone is going to bring for her'. So she was saying 'she was complaining, I thought she was lying but now I see what is happening'. So he told them 'if someone has to bring her food it's me and I'm here, how is she going to get the food? And she's not supposed to eat food from outside, she's supposed to eat the food from here because she is a patient here'.

[00:10:17]

And it was like they didn't want to make my bed, so he called the mother to call the Italian embassy, so they telling him... they called the police, the police told them to call the Italian embassy, the Italian embassy told them there's a number there I have to call because I'm in the hospital, they cannot just move me in the hospital [?] so then I told my husband 'I'm not going to take the medicine, if they're not going to change me from this hospital I'm not going...' So they gave me the medication, I refused.

So later is when, so I'm not taking it, and they became... I requested to talk to [missed] [00:10:58] so she came, I told her 'if I'm not taken to North Manchester I'm not going to take any medicine' so after that they transferred me to North Manchester. Actually, I had a bad experience I would say. I would say people are still [missed] [00:11:15] about it. It's made me scared because when I went to North Manchester I was still traumatised, I thought the doctors are still the same like Salford. I never used to talk to anybody, I just used to keep it to myself. Then when I said to have trust... to be honest I would say I don't have trust with doctors, I'll put it like that. Even nurses. Because I still have that trauma.

[Short silence]

[00:11:56]

**INTERVIEWER:** Okay. So you've talked about that experience, it sounds really terrible. Did you find anywhere to access support? In terms of when you did get your diagnosis or you overheard your diagnosis, and after you came out of hospital were you able to access any kinds of support, maybe through GHT or BHA? Or did that come much later?

**PARTICIPANT:** When I was there, because I was really poorly, because one thing shocked from being sick and the stigma from the hospital. My husband leaving me when I was critically sick. So I was all by myself. Then, because I was not talking to anybody, so it was when I asked if there's a place I can go, that is when they told me there is a place, George House, I can go there. I didn't go immediately because... when I was discharged, I think I went after two months. Yeah. I would say it's helped me, yeah.

[00:13:19]

**INTERVIEWER:** You talked about the stigma and maybe a little bit, and the kind of ignorance of the medical staff in a way. How do you think that affects people like yourself?

**PARTICIPANT:** It affects a lot because the trust you had for a doctor or a nurse is no longer there, because when you go to a hospital they are trained to treat you equally. But I come from Africa. I can accept it in Africa, but here, Europe, it's really a shame and very embarrassing. And these people are not... they're really educated, they don't care. Let the truth be told. Sometimes even when you go to your GP, they're telling you this, they'll ask 'how did you get it?' Nobody asks to be sick. Sometimes some people want, but some people don't. You should... like someone asking you, it just brings you down, you see. So for me, talking about medical, I will tell you I don't have trust. A few I have, but the trust I have, it's gone down. Yeah.

[00:14:44]

**INTERVIEWER:** Okay. So you mentioned you went to George House. Did you meet people there? What was good about... you said you'd managed to get a little bit of support.

**PARTICIPANT:** The thing was, first when I went there I was scared because after what happened to meet, seeing different people because you don't know who is who, you don't know who is there and you don't know how you're going to be treated. So they invited me to go to a coffee morning. So one guy, like, he suspected that I was scared so then later he was telling 'don't worry, you're [missed] [00:15:31]'. When he told me like that, that's when I had courage. It just lifted me a little bit, but I was not 100% sure he's telling me the truth or he's lying. So again when I went there is when I started to see people... people don't talk about it but I showed [?] many people. So slowly... like in BHA as well, people sit and discuss about it. In George House people just go, drink, they don't talk about it. So you don't know how to start to... it's a nice place, yes, but at times when you're traumatised, when someone talks about their experience it lifts your spirit up. Yeah, it's not like I want to come there to have a tea. Sometimes maybe when I come there I sit, we discuss, I feel happy.

[missed] [00:16:33] help, even George House, Positive Catholic too.

[00:16:41]

**INTERVIEWER:** Could you say a bit more about Positive Catholic, is it...?

**PARTICIPANT:** You don't know about it?

[00:16:46]

**INTERVIEWER:** No.

**PARTICIPANT:** They meet every, they had it last week, they meet once a month. Every second... I don't remember but there's a group for positive Catholics. Once a year we go to Newcastle [?], so we meet there, people from different places, they talk about their experience. Like last year I met one girl. People are making fun of her, she's not talking, but this year when we went she kind of opened up about her experience because she had a blood clot in the brain, so the husband left her in the hospital, the same like me. So it really helps, you sit there in the evening, you talk about the experience, you eat together. You just feel like you're at home, so you feel like, we have retreat together. Yeah.

So like, end of the month we meet, discuss what we've been doing, we tell our experience, how things have been. So I'm going back to give feedback but it gives me hope to go there and to give feedback what I've been doing. So it's like, it's making you move on with your life, to plan something ahead.

[00:18:19]

**INTERVIEWER:** Okay. How do you see your future, or how are you at the moment? You mentioned before that you've just had to move house. I imagine it's quite difficult if you, also when you're starting in terms of work and your home and also health. I guess I'm just asking about, how is it? It seems incredible to me that you've done so well to manage all these things that you're coping with finding accommodation, finding work and also dealing with this, the things that you've had to deal with.

**PARTICIPANT:** I think dealing with it, one thing is family. Supporting me to accept how I am. My cousin was trying to bring me down, he lives here. So the thing I did, my sister told me to just cut connection because I was going down. And then the organisation, they do help when you sit, people start to talk, it lifts your spirits. And then, I say I stayed home for two years. Staying home, doing nothing, it brings you down. That's my opinion. Because you are home, you wake up, you're just sitting there, you start to be depressed. Because I remember sometimes I tried to commit suicide because I was just feeling hopeless. I thought 'if I go back to work I have something to live for, I am not just sitting there feeling sorry for myself.'

[00:20:16]

You know when you're just there, saying 'what did I do wrong?' Like someone like me, my husband left me, I am sick. What did I do to deserve these kinds of things? You see. For me, I think working helps. When you work it helps a lot. It distracts you from thinking. So like now, if I wake up I go to work. When I come back I am tired, I just go to sleep. I don't have time to think. But if I just sit I start thinking 'what did I do wrong?' those kinds of things.

I had to move out. First I was homeless, because I stayed in the hospital for three months. And the landlord used to come and ask me for money when I was in the hospital, so they had to give me temporary accommodation. I was in the hotel, then they put me in temporary accommodation, then they gave me a house. I stayed in that house for, I would say now almost two years, but because it was having mould they had to move me to, because it was affecting my breathing, those kinds of things. So they had to move me to another place, to renovate it. But I am okay with it now.

[00:21:32]

**INTERVIEWER:** So you're back in that place?

**PARTICIPANT:** Yeah.

[00:21:33]

**INTERVIEWER:** And the mould is gone?

**PARTICIPANT:** Yeah, everything is better.

[00:21:37]

**INTERVIEWER:** Okay, that's good.

**PARTICIPANT:** Yeah because I had to go to George... because I called them, they told me I should be spraying [?]. Then I went to George House, I told them so they called them and they told them about my condition. I can't be staying in that place because it's affecting my immune system. So that's when they had to change me [?] to do something, they were not taking it seriously. I say, George House, they help sometimes. They do help when you need their help and make something happen, they stand there for you. Yeah.

[00:22:12]

**INTERVIEWER:** Okay. How do you see your future?

**PARTICIPANT:** [missed] [00:22:23] I don't know. I have a positive one. I don't know, I'm not planning. I would stay, I am still there at the moment, I am catching up.

[00:22:38]

**INTERVIEWER:** Day by day, taking it one day at a time?

**PARTICIPANT:** Yes, because if I say 'I am going to be this' I am lying, because sometimes I break down if I like it or not. All human beings, you come down. So for me I would say it's too early to say something.

[00:22:59]

**INTERVIEWER:** Great. Is there anything else that we haven't talked about that you would like to talk about, anything we haven't mentioned, any stories or anything that you would like to say?

**PARTICIPANT:** I think, what I would say, they should... people, they should stand up [?]. Especially this thing about doctors and GPs, because I feel more comfortable going to my consultant because he knows my condition, than going to my GP. I cannot be going every day to the GP. Sometimes, the way they look at you... but when you go to your consultant, you know they specialise for HIV. The way he would treat you is different. I know that some people, because at the time I was thinking about it, there was one lady who said she was treated badly in Salford. I'm not the only person, there were many people... if you go around asking, many people go out and they would tell these stories. So I think one thing, Salford is the worst hospital. It's not me, I've heard people complaining about it. They should be trained how they handle it. It's not about the specialities, even the doctors, they should do training. Because HIV has changed, it's not like before. Even a baby can have it, so the way that you treat them, even if you are a doctor, you should be taught how to deal with such things, such illness. It's not, if I touch you I am going to be sick.

Like, the BHA, there's one staff who works there, she cannot use a cup you are using. Yes. Most of the time they were talking [?] she is there, she is one of the seniors, and it's really shaming. Senior staff behaving like that and she's working in that department. So why are you working there? There are things people should see. I think people should change the mentality about it, they should just see it's a normal disease, it's not like before.

[00:25:14]

**INTERVIEWER:** Okay. If there's nothing else you want to add-

**PARTICIPANT:** Unless, I can't remember now. Unless you ask me. It would be easier if you ask them.

[00:25:32]

**INTERVIEWER:** Okay, you've just said that people need to change their mentality about HIV. Do you think things have changed? Obviously not enough. And how do you see that happening, that change happening? You talked about training, for example, for GPs and nurses. Yeah, in terms of society, do you think that change is coming?

**PARTICIPANT:** Yeah because if I look, like now, in Africa I think it's much better the way they talk about HIV because every family have lost someone. I've lost an uncle,

he committed suicide two years ago. So if you like it or not it's there, before people used to be shy, not talking about it. Now people are coming out, even they talk about it on TV. Even if you go visit, we have visitors. You go there, the way they counsel you, if you don't want to be tested you feel relaxed. But I've never seen it here, because the day I was like... the first thing 'you have to do it, if you're not doing it we're not going to treat you'. How do you expect... because when you grow up, you're told if you... HIV is not only [?] for prostitution, gay... you see. So I was a married woman, I have it. So of course my husband will have the mentality 'she was sleeping around', you see those kind of things. So people don't know you've got it in a different way, those kind of things. So I think they should try to teach people a lot. And I find it in Europe, for many people it is an African disease. It's not true, many whites have it but they think they don't have to be tested.

Even now when I got to George House I see old people have it and they're white, not even black. You see. So it's like, if they say 'we Africans, we have it' what about... for me, to see an old person, I see it here. Back home I was used to seeing mature [?] to go down, so you see those kinds of things. And people talk about it. Like my uncle, I think, for him it was like - he was a married man, he could not accept it. He didn't know how he... he married a second wife, so the stigma was, how is he going to face the world? How are people going to accept him? And this is the kind of person who never used to sleep around. They say those kinds of things. So if people try to teach it in a different way it will change more lives.

Like, I wanted to commit suicide in North Manchester. Yeah, yeah. Because I remember the day my husband told me he wants a divorce. He cannot stay with me. It was really painful because one thing was, I was still in bed, I was sick. He didn't know... thanks God he's not sick. So that day I was like, because normally they do switch off the light for people to sleep. So I was waiting for the nurses to switch off the light because I took the bed sheets, I went to the bathroom, I tried it in there because in the door, I put the bed sheets because I knew if I used it I could hang myself. It worked perfectly. So the thing was I was just staying awake to wait for them to go to sleep. And unfortunately they didn't go to sleep. The nurse was working the whole night.

Even when George House, I told one of the nurses, 'this is what I was planning to do that day'. They were really shocked. You see, for them it's like, when you give the medicine and you're coping they believe you're okay. You're not okay. Because if I didn't talk about why my husband was leaving me, nobody knew about it. I told my sister. My sister, she was shocked. She's in Africa, she used to call every day because she knew this one wanted to commit suicide. She still capable of doing it, you see. And like, some things when you go to tell people, nobody believes you. They will start to laugh at you, 'look, she's healthy, she's not capable.'

[00:30:05]

Like, after that I came back home. Staying alone, I lived by myself and I didn't know I was depressed. Depression, when it comes, it's a knock. [?] Even me myself I didn't know what it was, my sister's the one who told me, 'you are depressed but you don't know'. I took all the medication, I wanted to take all of it because what was I living for? I don't have a kid, I don't have a husband. I'm not losing anything. You see,

those kinds of things. That's, even if you go to George House they don't talk about those things. And they even sent me to a psychiatrist, I said to them 'I'm having this' and she's asking me 'do you think you're normal?' Already I've put me down, and since then I've not gone back. You see, those are the kind of things, they don't see it. Okay, maybe if I talk to someone you would tell me you can do this. It helps you but they don't talk about it. They don't talk about, when someone goes back home, what they're facing.

Like me, I was lucky. My sister was calling to check and then my friend suspect... when I told one of my friends he was really scared. So when I went to... I didn't tell the doctor but I told them 'I think I need to see a psychiatrist'. He was giving me medication. To be honest, I was not taking... if I can tell you I've taken that medication three times. I have them but I've never tried... the last time I want to take all of them to commit suicide. So when I went there the lady said 'are you thinking you're normal?' you say, someone telling you that. Already she has a mentality that you're HIV so upstairs you're not normal. Those are the kind of things people face but they're scared to talk about it, and people ignore, they know when you're on medication you're fine. It's not true.

People still suffer in closed doors. And you cannot be going every day to George House because if you go there already they will ask you 'do you have an appointment?' Okay I can go to BHA but maybe I don't have bus fare, or already that lady is there, so already people there are feeling not wanted. They cannot tell Priscilla. It's something they talk down. [?] 'For us she does people okay'. But already they feel like, you know, there's some illnesses that people are sensitive... immediately when I come to your house you give me the same cup [?] [missed] [00:32:28]. I don't like to go to people, I just feel like, even when I was at my sister's house I was using one cup. She asked me 'why are you only using one cup?' I was like, 'I don't want to spread illness.' She said 'see, you are the one stigmatising yourself'. I now say... I already have that thing in my mind so it will take me time to go... she said 'you think like that, I don't think like that. We are all the same'. That's one thing, you just have to accept yourself.

So I was saying [?] I don't feel comfortable going to people's houses, especially when someone knows you're ill. The way they will treat you, some people even when they greet you they don't want to greet you. So the best thing to do is to avoid visiting people, so I don't [?] go to BHA or the other side, but the way they were saying, you can't go to George House every time. They will ask you me 'why are you here?' Already that puts you off, so when you think 'why should I go there? I am not welcome.' So already it's not just that, you feel you're not welcome, so you begin to stigmatise yourself: 'is it because I'm sick? Or is it, what?' Already that thing brings you down emotionally.

**[00:33:56] End of transcript.**