

# Transcripts

**When Medicine Defines  
“What is Normal”: Image,  
Identity and Normality**  
Medicine: The Wellcome Galleries



## **Jamie: Actor, Father, Friend**

### **Jamie**

I don't wake up every morning going "Oh my God, it is another day being disabled." I wake up every morning thinking "Oh my God, it's another day of being Jamie."

My disability is an integral part of who I am. It's shaped my identity in many ways and people looking in at me may define me by my disability, but it's one of many, many characteristics that intermingle and are nuanced.

I am physically very different. I am physically very surprising, and the way I talk is a different way of talking. When people confront me for the first time, it can take a little while to get used to the way I talk. That makes people nervous about getting it wrong or whatever.

When I was growing up everyone stared at me because of my physicality and I got really fed up. And then in my twenties I became an actor. I just

think that is really weird, if you are fed up with people gazing at you, to then become an actor. But I guess it was something political and I was kind of in charge. And I guess at the root of everything I believe in, in terms of the acting - my life - I absolutely don't run away from my disability. It's part of the way I am.

# **Amanda: Nurse, Musician, Mother**

## **Amanda**

Working as a qualified nurse was a very interesting career to have. It was hugely rewarding but very full on, very emotionally and physically draining career as well.

There was a huge expectation to just give, give, give and not be looked after yourself. I was feeling very stressed, very anxious, overwhelmed and also worrying at the end of the day, that I hadn't done things properly or might've made mistakes. I had no evidence to suggest that, it was all in my head that I was doubting myself.

I never really spoke to people at work about it. We all tended to keep our heads down and get through the day. Then only after years and years and years of keeping going, did I suddenly then realise, actually, that's enough I can't keep going any longer, maybe I do need some help.

I had some cognitive behaviour therapy which was very helpful, and that was when I decided actually, I've had a long, successful career as a nurse and maybe it is time to take my pension [LAUGHS], so I did. [LAUGHS]

When I first decided that and I felt very guilty, that you're much too young to take a pension I was 55 years old and surely this is a sign of failure? But then when I thought about it and talked about a bit more with other nurses, and with my managers and realised that I had had a very rewarding and successful career, it was OK to be kind to myself and actually say: now look after yourself.

## **Horcelie: Believer, Dancer**

### **Horcelie**

I was diagnosed with HIV when I was 11 years old. When I heard it I thought it meant death. Despite the medication, despite how it can be controlled. As an 11 year old, I didn't know much. I didn't tell anyone, I didn't speak about it to anybody.

When I was 20 years old, after coming back from volunteering in South Africa I had another 6 months to do an 'action at home'. So I decided to join a beauty pageant. The plan was when I win I'd continue to raise awareness about HIV and AIDS in the African community in the Congolense community.

When I joined I decided OK, I'm going to keep it quiet, I'm not going to tell anybody anything at all. Then on the day of the show, that is when I decided to really go public. Instead of finishing it with what I said during the rehearsal, I finished it with, "My name is Horcelie Sinda Wa MBongo and I was born with HIV and this is my story."

I didn't know what to expect. HIV has such a negative association to it that people don't want to know about it. And I think often in life we run away because we don't want to face the issue. So I had that in mind and I knew as a young girl, what if I get treated badly? I just thought, why would God give me such a huge task? And I think that's when I regretted, I said: I wish I didn't tell people, because at least I'd still live a normal life, at least I can hide it. But I think even though I did hide it but I wasn't... I wasn't happy. So to me it's a liberation it's... it's overcoming as well.

In the UK, although there's stigma, I think we've come a long way. Like I always say at least there's now a conversation. The story has helped a lot of people... people send me messages, those who are HIV positive, those who have a friend, a sister. I see their hurt and I see their healing. Seeing the issue, speaking about the issue, but also overcoming it.

## **Amit: Sportsman, Teacher, Active**

### **Amit**

A lot of sighted people say that I've got good eye contact, that I look at them and they say, "Oh you don't look blind". But I don't know what a blind person should look like. [LAUGHS]

I can only see dark and light. I've got the condition since birth. As the years go on it gets worse. So, I've been using the long cane for about 18-20 years. Well some people, don't know how to sort of, approach visually impaired people. They want to help you desperately, and so they try too hard.

So, without asking you, "Do you like to cross the road?", they just grab hold of your arm and take you over. And then I have to tell them, "Get me back now. Cross me over back because I didn't want to be there". [LAUGHS]

20-30 years ago, I desperately wanted my eyesight to be cured but now, since I've accepted my eyesight

problem, I don't get up every morning and sort of worry about things like that.

Around 2009, I got selected to go to India to play cricket in the world cup. It was so inspiring. My parents felt so proud that I was playing cricket for England.

I remember in the 80's I was gutted because I couldn't play because I had my sight problem and I didn't know anything about blind cricket at that time. Through cricket and meeting other visually impaired people it gave me so much confidence that my life has just changed.

I've done so many good things. It made me feel good about myself.

# **Eleanor: Feminist, Daughter, Sleep-talker**

## **Eleanor**

I think some people imagine that dyslexia is that you find it hard to spell unfamiliar words, or maybe I have a limited vocabulary but sometimes when I'm tired I even struggle to spell my own name. It happens all the time.

I find it quite hard to look at a piece of paper and see the letters. Sometimes I can see lots of gaps in the page, or things swinging in and out of focus. It affects my speech quite a lot, so I find it very difficult to tell the difference between D's, B's and P's even when I'm speaking myself.

For me diagnosis opened up a lot of opportunities to receive help. It taught me about articulating what it was I needed and I think a lot of the struggles I'd been having in school, I had imagined that everyone found it so difficult to get through a book.

Being open about what you need and who you are is something that's carried through into my career.

Often it means that you learn more about those people around you and you realise that you are not the only person who is dyslexic or feels like this. But also I think my openness invites people to ask questions.

I wouldn't seek a cure for my dyslexia. I think it forms such an integral part of my personality and the way I approach life that I can't imagine not being dyslexic.

One of the things I kind of credit my dyslexia for is my creativity and that I don't just look at things from left to right like I'm reading them but I might look at things in a different order and in a more creative way and I think that sort of shone through my academic career but also in my career beyond that at work. I can't imagine being any different.