

# Transcripts

**When Medicine Defines  
“What is Normal”: Normality  
and Changing Perception**  
Medicine: The Wellcome Galleries



## **Alice and Daughter Molly**

### **Molly**

I think I find it difficult to remember what Mum was like before the aneurysm, I think because so much had changed. I never even thought that someone of Mum's age could have a stroke, because you picture it as old people have strokes. You can visibly see that they've had a stroke because their arms are low, their face is low. But that wasn't the case with Mum at all. She had a stroke, but you wouldn't be able to look at her and say, 'Oh, she's had a stroke.'

### **Alice**

What had happened is that the bleed on the brain had affected the area where language is processed. It did really feel like an elastic band had just snapped. I couldn't speak fluently, couldn't construct a sentence, didn't understand anything. Every single word I've ever spoken in my entire life had to be dragged out of what I would describe as mud – mud

in my brains. I was like a toddler having a meltdown, but couldn't tell you why – not really a nice person to be around!

## **Molly**

I'd go and sit with her, but it wouldn't feel like I'm sitting comforting my mum, it felt like sitting there almost with a stranger, just trying to get you to stop crying and so I can go and do my own thing.

## **Alice**

I did go to the doctor many times and said, 'No-one's come out to my family, no-one has helped my family.' I was desperate for someone to come out and explain 'this is what a stroke means' and things like that, in a way that it's not frightening, it's something that is just understanding as a natural part of an illness that affects the brain, which has basically put in front of my children a different mum.

My dad was schizophrenic. No-one ever explained what schizophrenia was, didn't understand how it affected my dad's personality and things like that. Thirty-five years later I can't see much difference – still we're in the similar position as I was as a child and no-one explained anything to us, nothing.

# **Sharon: Parent, Playful, Tenacious**

## **Sharon**

My doctor knew for years and years and years that I had this illness. He didn't tell me. He just kept saying, 'Oh it's a virus, you'll get over it.' People don't believe that I've got the condition because they don't see me on my bad days, they only see me when my body physically is able to cope with outdoor life.

On a good day I'll be bright, I'll be bouncing around and wanting to go out and wanting to do stuff and trying to cram in as much life as possible. And what the ME does, it suppresses my personality. I can turn from one extreme to the other and there's no in-between – from somebody being very, very active to someone empty inside.

I can go and stand in front of the kettle, I know exactly what to do but my brain and my body don't connect and I can't work out how to actually

make that cup of tea, and it's a spiral down and down and down.

A healthy person can do what they want when they want. But someone like me, who has ME, I'm unable to do what I want when I want or be able to be spontaneous. I'd love to be... I miss being spontaneous. At this point in time there's no fix, it's all about management.

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

### **Amit**

When I was around early 30s I was worried about what's going to be my future. Once I went to the Royal London Society for the Blind then I met other visually impaired people. And they were happy doing things in life, doing skiing, and going on holidays. That was my turning point.

I was beginning to not think of my eyesight problem, as I was spending more time with them. Now I'm happy to talk about my eyesight problems. I can even joke about my eyesight!

Society has come a long way with their awareness of how to help visually impaired people. You can hear things on the radio. They have to make adaptations for jobs, you've got to make sure they've got the equipment to use the computer, like speech software. Lots of changes on the trains and buses now. Bumpers on the platforms so you know that you're not coming too close to the edge.

But in general life there's always going to be obstacles. I've joined this dating site. I'm looking for a partner. Initially there's always a good communication, and once they find out that I've got a sight problem, they generally disappear.

My friend who's partially sighted, doesn't use a cane and he's had more dates than I have. And I'm not surprised, because his visual impairment is not visible. It does make me feel a little bit down for a few days. But yeah, still trying! You're only here once in this life and you've got to make use of it, what you've got.

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

### **Amanda**

As a child I was in a happy and normal kind of home environment. But when I was 11 my mother had a very severe mental breakdown. She needed inpatient psychiatric care and the mother that I knew was gone.

She became very deluded, had a lot of mood changes and was very unpredictable and volatile. It was a very difficult time and probably quite damaging at the age of 11.

My mother got limited support, which was mainly drugs. They didn't do talking therapy in those days. We also didn't get any support from the mental health services as the family affected by her illness.

I felt very let down by my mother. Now, looking back, I would say I was let down by society and the medical profession, but I didn't understand all that and so I was angry and upset with her.

Mental health and mental illness was considered a sort of taboo subject, so we just had to get on with pretending that things were OK. I think it did make me more prone to anxiety, definitely. I learned to not talk to anyone and not admit any struggles, and that's what life is.

I think if that was to happen now, as a family with young children with such a severely ill mother, I'm sure we would have been helped and looked after a bit more.

## **Jess: Friend, Sister, Swimmer**

### **Jess**

I've had type 1 diabetes since I was five years old. Every time I eat something I'll have to work out what the carbohydrate content is. You have to monitor your blood sugar levels and inject insulin multiple times throughout the day as well.

It is quite unrelenting, because there's not really a time when I can just switch off from it. I think people do think living with diabetes is easier than it is, because it's quite invisible and people get so used to seeing you just coping with it and dealing with it.

In my 20s I started to take things much more seriously. I knew I was over-testing and over-worrying about it – wanting to control things and be strong, and not really admit that actually it was making me feel really rubbish.

On paper I'd go to hospital and they'd say, 'Oh you've got really good results, and you're doing really well,' and actually I was on the inside feeling quite stressed

and overwhelmed about it. I never really knew how to be honest with them and say, 'Oh actually I need a bit of a break.'

One of the hardest things for me about living with type 1 diabetes is that it both affects how you physically feel but also how emotionally you feel as well. Even rising and falling blood sugars might change my moods. It's really difficult to separate out where I begin and the diabetes begins, and what the boundaries are between those things.

So when I started getting help from a specialist diabetes psychotherapist, someone who both understood diabetes but also really understood the emotional and mental health side of it too, I felt like I could breathe for the first time and that's when things started to change.

Getting extra support has made me feel a lot less lonely, because I feel like I was being taken seriously as a whole person and not just a person with a condition. It seems almost surprising that it's not more widely available and just a normal part of diabetes care.

