

Transcripts

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

Gifford: Brother, Son, Chef

Gifford

It could happen to anyone, basically. One in four people get it, suffer from mental illness. I was about 19, 20. My girlfriend's mum come and said, 'Oh he's not well, let's get the ambulance.' So they took me to the general hospital that was just down the road.

There's a little label down near the bottom of the medication saying that it could cause this and that. Maybe you don't want to be doing that? I've been taking it for about nearly 40 years now, so maybe I need it. I keep relapsing, going into hospital, not taking it. So I'm just taking it now.

You're caught up in it, your label. Like a catch-22 situation, you know? There is good parts about it where you can get help from different organisations, different charities will come and help you, and you can speak up for yourself and make an opportunity out of it. There's good and bad things about it.

There is some stigma about it. People will just be people, basically. Stick to the people that know about this illness. They will understand where you're coming from. Most of my family understand me. And doctors and nurses when I go into hospital, they can be very friendly and sympathetic and cheer you up. It was my birthday in there one time and they kept a party for me, so that was very nice.

It's an improvement coming up from where it used to come from back a few decades ago. Like an asylum system where you were locked up and you couldn't go out. It was very strange the first time, going into that kind of system. You had to adapt to it and get used to it.

It's a good thing equal opportunities, equal rights came out. Give you a chance to communicate or acknowledge you and treat you as equal. Some people look at you and they'll be discriminatory, yes, but it's only a certain percent.

Helen: Friend, Crafter, Advocate

Helen

My name's Helen. I'm 24 and I have fibromyalgia and chronic fatigue syndrome. Until I found that label and found out what was going on with me, I had no-one in my life with similar symptoms, so I had no clue what was happening.

They're both dismissed a lot or they're both misdiagnosed as something else, but I was really lucky that my GP listened. She understood that I knew my body better than her and we were just figuring out, together as a partnership, what could be wrong. So she took the chance on me, realised that she didn't know everything and sent me off to a specialist. Best day of my life.

The amount of people who dismissed you because feeling tired is feeling tired, having a bit of pain is a bit of pain. But when you can say, no, I have this disability, this is my diagnosis, most people begin to take you a bit more seriously and listen to you.

It was like a massive weight off my shoulders. I had a word and that word I could go away, I could take with me, I could reclaim, and it empowered me. And for me it was like finding the way to be like, yes, this is me, how do we deal with it?

I guess that's when I went away and tried to find where I belong. And that's where I found my community of people, similar aged, on social media all around the world, experiencing what I was experiencing and knowing that I was not alone, and it was amazing [laughs].

We're not just sitting back and taking it, we're accepting that this is our diagnosis and we're going to fight and continue, and we're going to show that we exist in this world. This is our reality.

Sarah: Artist, Mother, Londoner

Sarah

I'm Sarah Ezekiel and have been living with motor neurone disease for 18 years. At the age of 34 my diagnosis was like a thunderbolt and changed our lives for ever. I found out when I was pregnant with my son, Eric, and a full-time mum to my daughter, Aviva.

My neurologist didn't give me a prognosis. I'm glad that she didn't. I found out later that unfortunately a third of people with MND die within 12 months. I have defied the odds and my children are now 21 and 18.

At first, the feeling of isolation was awful. I became depressed. Losing my speech was like losing my identity and personality. Some people speak to me like I can't understand them. It's been the worst part for me. I never imagined that things could turn around, but they did.

One of the biggest changes was when I was introduced to assistive technology. I was able to

surf the net, read and communicate again. And I used the internet to raise awareness of my condition. Now I am speaking to you using an eye-gaze computer. An infrared bar tracks my eye movements.

Once I discovered eye-gaze painting I couldn't stop. I had always wanted to be a fine artist. Although terminal illness and severe disability can seem hopeless, the human spirit is incredible and people adapt. My medical label doesn't represent me in my mind.

Eleanor: Feminist, Daughter, Sleep-talker

Eleanor

I've always been dyslexic, but in the past two years I've lost nearly all the eyesight in my left eye due to a severe form of uveitis. At the moment, I'm deciding whether or not I'd like to register as partially sighted.

The purpose of registering is so that you can receive additional support that you're entitled to. But I could lose all my eyesight and still choose not to register as blind and not give myself that title.

I do have limited vision, that's true, that's something I'm happy to tell people, I'm very happy for people to know. But it's about identifying myself as a stereotype or an assumption that people might make about me.

I was talking to a blind friend and they were saying that people were amazed that he'd managed to cook dinner. And he said, 'Well, if people really knew me they should be amazed because I'm a terrible cook. But they shouldn't be amazed because I'm blind!' And you do often experience a kind of

air of surprise when you arrive somewhere on your own, or lots of people who are blind in one eye still drive and people assume that that's ridiculous. But actually there's not a lot of understanding about how independent a person can be when they have various different impairments.

I'm not at the place where I need to register yet. My eyesight's still deteriorating. I think I'd like to be able to make that decision before my sight deteriorates so far as I feel like I have to make that decision. Most disabilities are assigned by doctors. It's a label that you might be given at birth, or some time through your life. But usually that decision is made by a professional. And I think the emphasis on it being my decision makes it a hard one.

Rek

Rek

When I was 24 I suddenly started having a pain in my right foot. After about four or five months I got the diagnosis of arthritis. When I spoke to my friends and family they had the same sort of thought as myself, that, 'Oh, you're a bit young for that.' I couldn't do all the things I perceived a 'normal' person that age would be doing.

I kept saying to my doctor, 'So, when I get better I can go and do this? And so when this gets sorted I can go and do this?' And he had to say to me, 'You're never going to be that person any more.'

I had a lot of moments where I was like a petulant child and was like, 'This is not fair, why me?' And over time it became very much like, 'Well, everyone has their time.'

Travelling for me was something that I wanted to do from a very young age. I used to spend every spare minute and spare penny planning and looking towards my next trip. And I was able to do all sorts of backpacking, working on a banana farm, whitewater rafting. But obviously that was before I was unwell.

I was diagnosed very early 2005 and I moved to Hong Kong in September 2007. And it was a challenge, not just because it was physically tough but it was also tough to sort out all my medication and my care. But four-wheel suitcases are revolutionary!

I call my arthritis Arthur, so I just say, 'Oh yeah, Arthur's not feeling very well today. Poor old Arthur.' That humour is important, I think, because it diffuses any situation usually. It's a habit for me now, just like I've got dark hair. It's... I've got arthritis. It's part of my make-up in that same way.