

Transcripts

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

Sharon: Parent, Playful, Tenacious

Sharon

That Christmas, my partner and I went down with a common cold. Within a couple of days Conor was back to normal and I pretty much stayed bed-ridden for near enough 18 months. That was when I found out I had ME and that was really when my life came to a complete full stop.

I was really lucky with Conor because he already had an understanding of ME because his Mum had it. He's great, he... he does everything I don't have to worry about anything to do with the home. He goes out of his way to make sure just like simple little things so I don't have to use up lots of energy. Like physically or mentally.

All these years later I still feel I'm pulling him down with my condition because I feel that I'm stopping him from having a life. Many a person even my friends come round and say 'But you've got Conor,' which I think is a bit naughty really because Conor needs a break as well, as a carer.

In terms of my family, I've got quite a pretty good relationship with my granddaughter and for her age she's quite understanding of the medical condition but I think it's because it's always been a part of her life since she was young. She's seen my ups, she's seen my downs so she'll know when she phones me, she'll go 'Oh, you're ...you're tired Granny, oh I won't keep you.'

We'll plan it so that she can only come over on a good day so I'll make sure that I've rested, pretty much 3-4 days, up to a week. When she comes over taking her to the park, that wipes me out so the following day I wake up and I feel like I've run a marathon or two, or three.

Once I start doing stuff there's gonna to be the price to pay and it's the way the condition makes my body react and that's payback. I bargain an activity against the consequences. With the support of my partner we've found ways to, you know, improvise and adapt our life to enjoy the good moments and just cope with the negative moments as best we can.

Ruth: Encourager, Carer, Organiser and James: Son, Warrior, Survivor

Ruth

I'm a mother of two wonderful young men, one 28 and one is 22. They both have sickle cell anaemia from birth. When we first got the diagnosis it had quite a big impact on us as parents. It was a shock there was a sense of guilt because we thought we had given this child this illness.

And we were isolated because we didn't know any people that had children that had sickle cell and in our culture it was something that you don't speak about because it makes you look as if you're less than a parent, you know 'you've caused this problem to this child'.

James

When I was growing up, if I was at school and my friends would play football or go running, obviously you try and do those things because it's new and you're a child and you want to have fun. But then you would come home and you would be in pain or you would have a crisis or you'd be in hospital the next day. You have to learn how to do things differently, so instead of going out and playing for an hour, you got out for 5 minutes you come back.

Ruth

Mmm hmm.

James

You'd drink water, you take your tablets. You can still hang out with your friends but you don't do everything they do.

Ruth

There were many times we had to go into the hospital, when the doctors would come and they would perhaps just deal with the effects of the sickle cell but not think of the side effects. As a parent I had to fight for them, be their eyes and ears and their voice.

James

It's definitely made us closer. I was home-schooled a lot. Didn't really go to nursery or anything like that. I'm so proud of my Mum and Dad for getting through it. They've sacrificed and they've dug the tunnel for me to walk through.

Ruth

When you're in hospital and you know, it's sort of the wee hours of the night it's amazing the conversations that begin and the things that come out that you would never have known before. In spite of the illness

I've sort of valued that time where we have shared things that perhaps we may not have had time to share.

We've always said don't let the sickness define you. You can achieve whatever you want to achieve, you may have to take a different route, you may have to take a little bit longer, but you can do it.

Alice: Resilient, Creative and Molly: Adventurer, Inspirational

Molly

I was 15 when it happened. I remember we weren't really told what was going on we just knew: Mum's in hospital. Literally nobody, so not even family would sit with us and be like 'Alright this is what's going on', they'd just be like 'Are you OK? How are you dealing with everything?'. But we didn't know what we were dealing with and why we wouldn't be OK.

Alice

I didn't really know what was happening. I had pipes coming out of me and in all these various places and apparently was shouting 'No no no', and pulling things out. It was an aneurysm.

I spent a couple of weeks in intensive care. About 3 days in I had this vision of my three children, Molly, Joel and Tom. They were at my bedside, they didn't

say a word, they were just there looking at me. And I said, “OK, you win, you win. I’ll fight”. That was a decision I made to fight to live. It was the hardest decision I’ve ever made, because it would’ve been so easy just to slip away.

Molly

I think it did affect us quite a bit in the long haul. We didn’t know that she couldn’t explain it to us, we didn’t realise how difficult it was for her. We weren’t very sensitive towards what she was going through.

Alice

I wasn’t able to parent. You know whilst your going through the years of growing up as teenagers, I wasn’t able to function in the way that I did as a parent. Tom, as my youngest child, probably felt it emotionally the most, because he was 11.

Molly

He had like a full-on meltdown.

Alice

Yeah.

Molly

Yeah, he did not know what was going on. He was screaming, crying.

Alice

Molly also had her own issues, mental health issues. Whether that was a result of me being there or not, I'm pretty sure some of it didn't help.

Molly

Before we'd go shopping, we'd do girly chats, and anything like that completely came to a halt so, if I

ever wanted advice, there was Dad to go to which ... you don't really want to talk to your dad about those kind of things.

That's why when I wasn't very well myself at uni, I'd just avoid home, I wouldn't go back. But now Mum's a lot better, I love being at home. And I think it's because we can appreciate each other for what we've both been through, and respect each other for that as well.

Isabella: Daughter, Editor, Traveller

Isabella

It was very strange the process of finding out that my mum was bipolar. It was just like a whole part of her that I never knew existed. I think I must have been about... maybe 37 at the time. It made me just reevaluate my whole childhood. Things were actually difficult for me growing up, but I just sort of thought it was normal. And I suppose I always felt that things were on the edge of going wrong but it was never talked about in terms of mental health issues.

And I think that put a lot of pressure on us as the children because we were having to make sense of it, but without being given any information with which to do so. I think the knowing helped. Made it possible for me to feel kinder to myself for perhaps not being a superhuman 6-year-old, or whatever, and not sort of being able to manage better than I did.

If I had developed bipolar then I would have been at sea and I wouldn't have known how to deal with it.

And I think that's a real problem if people hide their medical conditions 'cause then as it travels down the generations people aren't prepared. If you're prepared it's not all about fear sometimes it's about knowing what you can do which is less scary.

I have a condition myself called Ehlers-Danlos Syndrome. It's a genetic condition which is a connective tissue disorder which means that I injure more easily and it takes me longer to heal. It's led to me having chronic pain which I've had for the last 10 years as a result of various injuries.

My Mum's diagnosis has made me feel much closer to her. Especially because I have an invisible disability myself. I just feel like she missed out on having that emotional support and if we'd known she had bipolar...then...we perhaps could have understood her better and been able to help her a bit more. And you know that... that makes me feel love for her inside. And I'm glad I know that 'cause it would've been awful to have found out you know... too late when I didn't have the chance to feel that empathy with her.

Jamie: Actor, Father, Friend

Jamie

I was born in London in 1966, many many years ago. I'm the oldest of three kids. I wasn't treated any differently than the other kids and I guess that's why I am what I am today. A lot of it goes back to my parents and particularly my mum, I think.

I've got a lovely family around me. I've got my partner Jo and two kids. Louis who is twelve and Willow who is nine. And they're cool. It's a pretty normal family setup. We've been arguing all morning, so... yes. I'm definitely just Dad to Louis and Willow, they are completely cool about it, I mean, they've grown up with it, they don't know any different.

Over the last couple of years things have become a bit harder in many ways. I was walking and now I am in a wheelchair. I haven't got as much co-ordination and I'm no longer as independent as maybe I was. My partner Jo has to do more around the house. It's an ongoing thing and we're all working together to make it OK.