



## Living with Disability

*Living with HIV: illness and Identity*

**Sian:**

Can we talk first just about haemophilia. When you look back to your childhood, and maybe your young adolescence, how did you feel about being a boy with haemophilia? Owen?

**Owen:**

My main memories of being a child with haemophilia, when there was no treatment, was the pain of getting bleeds, the time that I used to spend in hospital. I used to be embarrassed is probably the word about it. I didn't want to talk about it, because when I used to go back to school after having a spell in hospital, it got so boring. Because no-one really wanted to understand about my condition, about having haemophilia. None of my fellow students or the teachers. So I'd come back into school and they'd say 'Where have you been for three weeks? Hurt your foot again?' And I just found that quite tiresome.

**Sian:**

How did you feel about being different from your mates, from your friends?

**Owen:**

I did feel different when I was ill, either when I was in hospital with a bleed, or when I was at home with a bleed, and I couldn't go out and do the things I wanted to do with my friends, then I felt different. But the rest of the time, I don't think I felt different at all because I just got on with it. And I used to play football, and do most of the other things that the other kids did. So I don't think I did feel that different. I only felt different when haemophilia actually impacted on my life.

**Sian:**

And Mick, you didn't go to a statutory school. You went to a special school for children with disabilities. How did that feel for you?

**Mick:**

I just couldn't understand why I was there. Because I was relatively, or seemed relatively normal, compared to everybody else, you know, I wasn't in a wheelchair permanently. Wasn't sort of mentally handicapped. Fully compos mentis. Probably was, one of the, if not the brightest kid at the school, because you know, I didn't appear to be that disabled.

**Sian:**

Do you know the rationale behind the fact that you did go to that special school?

**Mick:**

Yeah. I mean it was a combination of a few things. One, just, my parents were told that no normal schools could cope with a haemophiliac, because of the bleeding and having to have treatment, and things like that. So rather than put up a fight, they say 'okay', and just dumped me in a special school, for the uniquely gifted.

**Sian:**

Owen, with you I remember when we talked before, you made a really interesting comment about, it was very hard to be a man when you bled. Can you just remember when we talked about that, and can you expand on that a bit?

**Owen:**

Yeah. I think what I probably meant was that being a man you are supposed to be physically strong as well as emotionally strong. And having haemophilia, either before treatment became available when I was about fourteen years old, or even after, because my joints were damaged by then anyway. You couldn't always do the physical things that men are expected to do. And as I grew up, and when I became a teenager, I think that became worse. And I probably still do have problems with that. If I see someone, a woman with a pushchair on the underground, and I have a sore elbow, I will still go and help her take that pushchair up the stairs, because no-one else will do it. And half of me is saying 'don't do it, because it will hurt, and you might need some more factor treatment.' But the other part of me is saying 'I can't just watch her doing it, because it feels wrong'.

**Sian:**

So, when you were both then young adults, HIV came along. And you were both diagnosed with HIV. Did that change the feelings that you had about yourselves, being positive? Owen?

**Owen:**

Yes. It did for me. Ironically I was infected in 1983. I wasn't told until approximately 1985/86, I can never remember, and there's nothing in my notes to say when I was told. But I would say it was roughly about then. And I was in my late twenties. And ironically, it may sound a late age to do so, but I was just coming to terms with living with haemophilia. And there was this treatment that we were using. And despite the fact that it was giving us a bunch of viruses, it actually worked. And that revolutionised some of our lives, in that it worked. And I remember that I was coming to terms with it. And finally at that age, I was starting to talk to people, and when I met girls, and when I met other people, I was quite happy to say 'I've got haemophilia, and this is how it affects me'. And then within about a year, and I remember this very well, of coming to terms with it, I was told 'oh, you've got.. which then wasn't called HIV, it was called something else.. but basically what I was being told was 'you've got AIDS mate, and you probably haven't got more than three years to live'. So that set me back. Well, it would set me back anyway. But it was just, thinking back, very frustrating that I was coming to terms with having haemophilia, and then I was given this news.

**Sian:**

Mick?

**Mick:**

I had a diet sheet come through the post. And on one side of it, it said 'this is what you eat if you are HIV positive'. And on the other side it said 'This is what you eat if you have the AIDS'. And I remember it, because at the bottom of both sides it said 'one pint of bitter', which I thought 'that's not too bad then. It can't be that bad if you can still have beer'. So I phoned the haematology unit up, and they said they couldn't possibly talk about it over the phone. Got to make an appointment with the haematologist, so I made one. And then thought I can't wait. I phoned the GP up, and the GP said 'yes, he'd known for eighteen months'. He was quite shocked that they hadn't told me. So I went to the haematologist, who within the space of about a minute, told me 'Yeah, I'm sorry, you have got Hep 'B'. You've also got HIV. You've probably only got about six months to live, so go out and enjoy yourself, but don't have sex'. It's like telling an eighteen year old to go out and enjoy themselves, but don't have sex. It doesn't compute really. So I think, to a huge extent, I just stuck my head in the sand, and just carried on with things.

**Sian:**

How about you Owen? Did you disclose the information to friends, family?

**Owen:**

I basically told nobody. There was a local HIV group, support group, being set up in my home town, and I shared that with those people, when I met them. And I told one other friend. But I don't think I told anyone else for about two years. And I remember very well a few years ago, coming across, I was moving, and I came across some of my pocket diaries, that I had used over the years, and I had kept. And for two years after I had been diagnosed, all that was in those diaries, was my work commitments. I was working shifts in a Care Home. And all that was in there was my shift pattern. Nothing else. Nothing personal. I had a social life. But I'd

written nothing in it. And that was just really weird. Because that sort of coincided with the two years that I didn't tell anyone, and drank a lot more and took a lot more drugs, and basically as Mick said, buried my head in the sand and pretended it hadn't happened.

**Sian:**

Why didn't you tell anyone?

**Owen:**

I was scared. I didn't really know what it meant. I expected to die very soon. I didn't want to tell my family because the reason for me for telling someone would be so that person could support me. And that would be the only reason. So I didn't tell my parents, and I haven't told my parents to this day. Because they would have not have been able to support me. And that's not a criticism of them, they just wouldn't have been able to do it. And they would have spent the time worrying about me. So my feeling was 'well don't tell them, because it will just worry them'. And over the years I've found people that I can talk to about it, and people who have supported me, and that's great. But that's why I didn't really tell anyone. I suppose it's just incredibly scary. If it doesn't happen to you, you have no idea how scary it is to go to the hospital with one long term medical condition, that is a pretty scary one on it's own, haemophilia, and to be told suddenly you've got this virus that is probably going to kill you very soon.

**Sian:**

And the public reaction to what was going on at that time. Do you remember. How did that impact on your decisions to tell or not to tell people? Mick?

**Mick**

All you saw was those tombstones coming crashing down, and it was you know, every time you picked up the paper, it was the 'Gay Plague', or a load of drug users have got HIV. For me, it was like well, what's the point of causing myself unnecessary pain by telling people and being shunned away, and things like that. I didn't want to be.. I wasn't homophobic, but I just didn't want people to think I was gay. Because that isn't how I caught it. I wanted people to know how I caught it. But I thought 'well I can't say anything, because you just presume'. I remember being at work once, and there was a big three or four page spread in the middle of the Sun, and it was another haemophiliac in Birmingham that actually infected a girl. And I remember the comments made in the office, were well 'it's his own fault'. 'He's probably gay anyway, and he deserves to die'. And for me, from that point on, it was like 'I can't even tell anyone I'm a haemophiliac' because if that's the way people think there is no way. So for me, I wouldn't tell anybody I was even a haemophiliac from that point on.

**Sian:**

When you talk about this time in your life, like you say, you were told you had six months maybe at the maximum two years to live. You live a very different life now, and you are now both on anti-retroviral therapy. Does your feeling about who you are, as a person with haemophilia and HIV differ now, because of that drug therapy?

**Mick:**

Yeah. I think, the first few years, you're expecting to die. So for me, it was just to live day by day. You know. Spend all my money, enjoy myself. Have fun really. I would say the first three or four years were really good. I run a load of catalogue debts up. I had a half sized snooker table in my bedroom. I couldn't actually play it because my bedroom was too small. But stuff it, I had fun. I used to buy my friends all drinks. And I couldn't afford it, but I wasn't going to have to pay for it. So..

**Sian:**

How about you Owen?

**Owen:**

Yes, I mean everything has changed over the years. Because we've all been infected for longer than twenty years now, which is quite incredible, thinking back on it. Because I remember leaving the hospital when I was diagnosed, and I remember very well how I felt.

And the fact that basically my life was over. And now over twenty years on, and I basically just got on with my life. There were the two years when I freaked out and hid my head, and took loads of drugs and drink and things. But after that, I started getting my act together. And it shaped who I am, and I think it's had an awful lot of influence in the decisions I've made in life.

**Sian:**

Mick, when you talked earlier on, you were saying about the people you didn't tell and that you never spoke to. And yet our relationship since 2003 and with Owen and I a lot longer, you now talk a lot about your condition. How does that help?

**Mick:**

Not having to lead two separate lives. I've spent so many years. I had my personal life with my wife, where we could talk about it on our own, in our own home. But as soon as we left the house in the morning, and shut that front door, then it was just about to lead a totally separate and different life, to the one we had indoors. Because we had to watch exactly what we were saying. Make sure we didn't spill anything out. Make sure we covered ourselves if I had to go for a hospital appointment, or a check up or anything at all. And it was just.. the first ten years of our marriage, it was just like leading completely separate lives. And to do that, and the stress levels, to try and maintain that and keep it up, it's horrendous. All that's gone. It's like a huge weight gone.

**Sian:**

Now Mick, you're very open now about your diagnosis. Extremely open, to everyone that you meet.

**Mick**

Overtly! (Laughter)

**Sian:**

But Owen, that's still not the case for you, is it. Can you just talk about where you are, with this idea about disclosure. Who do you talk to and who don't you?

**Owen:**

Well firstly I should say that my real name isn't Owen, it's a name I use for doing things like this. And I suppose the main reason is because.. I am exactly the opposite to Mick really. I am married and I have two children. When I am at home, HIV is just not an issue. It's not something I particularly talk to my family about. Because I don't need to talk about it. I get my support by talking to people like Mick, and you Sian, and other people I know, and other people I work with. But when I'm at home, it's really not an issue, unless I'm poorly, and I haven't been for a few years, so that's good. And, I live, I basically live a lie. People don't know about me, where I live. My family don't know about me. And that's something I first of all, I didn't tell people as I've explained, because I didn't think that my family would be able to support me. And then I think when I had children, that was a decision my wife and I had to take. And I remember us very well talking about it, and saying that at some point, we're going to have to discuss whether to tell them or not. And sort of it never really.. what age do you tell a kid? You can't tell them at two or three, because they wouldn't understand. So then you start thinking, 'well do you tell them at six or seven, eight or nine?'. And now they're teenagers. And a lot of people think that that's really weird, and they think that I'm a bad person because I don't tell them. Which doesn't bother me, because there are a lot of things in my life, and my wife's life, that my kids don't know about, and will never know about. There are things in my life that my wife will never know about, and I'm sure it's the same the other way round. So it is I suppose, it's a secret. And I suppose I live a lie. But I've become so used to it, that actually it doesn't bother me any more.

**Sian:**

If you were at a party and you met somebody, is there ever an occasion you think you might actually say 'I have haemophilia, and I'm infected with HIV', to somebody that you met for the first time?

**Owen:**

Not in my social life in my home town, or with my friends, or family. But then I suppose I'm really sad, because a lot of my socialising is done at conferences. Where people either have HIV..

**Mick:**

In a safe environment.

**Owen:**

In a safe environment. And that is quite therapeutic for me. But I don't think, thinking back on it, thinking now, no I would never do that. If I was with my wife or with my other friends and I met someone. And yet, I am quite happy to do it, when I am with a group of doctors, nurses and other people.

**Sian:**

What about you Mick?

**Mick:**

God yeah. If they ask me. I wouldn't.. I wouldn't volunteer it out, because what's the point. I don't volunteer out what I do as a job. I don't volunteer how long we've been married. How many girlfriends I had previous to Caroline. It's not something you do. But if somebody turned round and said 'You're one of those haemophiliacs, are you HIV positive'. I would say 'yeah'. Not a problem at all. If you've got a problem with it, go away. If you haven't, ask me more.

**Owen:**

I don't tell people because it's a part of my life that's actually none of most people's business. I don't want to meet someone at a party, and they're gonna say 'I've got cancer. Do you want to know about my cancer?'. Unless I get to know that person and become attached to them, I don't want to know it.

**Mick:**

If you see somebody at a party and they've got no hair. And if you're like me, I'd say 'Oh what's going on there? What's wrong with you?' I would ask them. Would you want them to lie to you?

**Owen:**

No, I wouldn't.

**Mick:**

Because by doing that, for me anyway, it perpetuates stigma. It just carries it on. Unless people stand up and say 'Yes, actually I've got HIV, stuff you lot'. This is how I got it, not my fault. Whatever. Unless people start doing that, the stigma is never ever going to go away.

**Sian:**

I think the interesting thing in what you're saying actually, there's lots of aims to disclose. And it could be personal, you just want to talk about yourself. But there are political aims aren't there to this. And there's also the issue about reducing stigma. And I suppose there is a lot of reasons you may or may not disclose the information.

**Owen:**

Yes. But part of the reason, and this is where I agree with Mick. That we have all been infected now for over twenty years. And almost all of us do not think it was an accident. And one of the reasons that not much has happened until recently about that, is because we have been almost programmed to be quiet. And embarrassed. And most people have been like that. And that's why I have a tremendous amount of respect for people like Mick, and other people who will stand up.

**Sian:**

Can I just ask one question, one last question to Mick? And that is that, you are very very open now about it. But you weren't once.

**Mick:**

Nope.

**Sian:**

How did that change? What was the moment that you changed?

**Mick:**

I can tell you the exact date of the moment. It was January 31st 2001. Up until that point I was quite open. I had become a lot more open than what I used to be. All my family and my friends knew. Everybody around me knew. But I came home from a weekend in London, I think it was midweek. I had taken my wife to see The Lion King for her birthday. We can back on her birthday. And in the post was a letter from my haematology unit, saying that I had been given fifty bottles of Factor 8, that was donated by somebody who had just died of Variant CJD. So theoretically I may have variant CJD. And for me that was just the last straw. The same day, I gathered all my blood products up. I took them back to the haemophilia unit. I threw them at them, and told them to stick it up their arse. I'm not coming back until I get the new synthetic stuff that wasn't made from human plasma. We were fostering teenagers at the time. I told the, I told one of the foster kids social workers. Literally in a probably a two minute phone call. Because they didn't know anything. I said 'Look, I've got to tell you, I'm a haemophiliac. I've got HIV, Hepatitis 'B', Hepatitis 'C', and I've probably got a new variant CJD now. So I'm going to the press today, and you need to know'. She went off on long term sick and never ever came back again to Social Services. But that day, also that day, by the next morning, I was on Sky News, BBC News, I was on every news you could think of. All the papers. Because I just went to everyone and thought 'stuff this'. And I've always been the person. If you're going to do something, you've got to do it properly. You've got to do it in one big go.