



Living with Disability

Living with HIV: Identity and support groups

Sian:

Mick, when we met and we did a long interview, and you talked to me about a lot of parts of your life. One of the things that was particularly interesting, was your story of how you heard about a support group. And how you felt about the idea of joining a support group. Can you just go over that?

Mick:

Yeah, it was Birchgrove. We had a, I don't know if it was a flyer or an application to go on a weekend away. Self-help weekend away. Positive Haemophiliacs coming together. And I remember just thinking there's no way I am knowing to a freaking namby pamby weekend of a load of whinging moaning self pitying haemophiliacs, going on about their blood disorders and their viruses. I just didn't want to do it. And my wife made me. I'm not quite sure how. But she got me, she took me kicking and screaming. And I could probably say it's one of the best weekends I've ever had in my life. It was just a revelation to sit in a room, and listen to people saying the exact same things I'd been thinking and saying for years. It was just a huge relief.

Sian:

And Owen, I think if I remember rightly, you also had fairly negative feelings about the idea of getting support from peers, and other people with haemophilia. What are your feelings on this one?

Owen:

When I was first diagnosed, that day at the hospital, I wanted nothing to do with anybody else with haemophilia. Because I was assuming that the majority of the ones that I met would be in the same situation as me. I was scared. I wanted and I needed to be strong. And the last thing that I wanted was to talk to other people with haemophilia and HIV. Because I expect I was scared that I was going to die, and I was scared that they were going to die. And it was just all too much. However, when I was first diagnosed, one of the first things I did, was go to a weekend run by an organisation in London called 'Body Positive'. Which was mainly about 75% gay men and a few straight women. I was the only straight guy there at this weekend. There were about 60 or 70 people. And it was a turning point for me. Because just as Mick has said, although these people didn't have haemophilia, the majority of these people were gay men who had been diagnosed with HIV roughly the same time as me. And what was good for me, was it didn't seem to matter, the fact that I got it through blood products, and they got it presumably through sex. That wasn't an issue for that weekend. And I learned an awful lot about myself, and thinking back on it, probably subconsciously, made decisions that I wasn't just going to give up, and I was going to try and get on with my life. So that was very important to me.

Sian:

You made an interesting comment there, when you said I needed to be strong, and if I met people with haemophilia and HIV, does that mean you feel they wouldn't be strong or wouldn't allow you to be strong. What was your thinking about that?

Owen:

I think I saw, and I got myself in trouble with this before. But, I am still going to say what I think. I think I saw a lot of the other people with haemophilia as weak. A lot of the people I met at that time with haemophilia, were affected by it far worse than me anyway, never mind HIV, and I didn't really want anything to do with them anyway. Because it sort of reminded

me of what I had, and a very selfish thing indeed, but yes I think I saw most of the people I met at the clinics as being weaker than me.

Sian:

Mick, when you were talking about the idea of getting the letter from Birchgrove, and you had this view that there would be all these people sitting around, feeling sorry for themselves. Where did you get that idea from?

Mick:

All self-help groups were a bunch of namby pamby's, that's what I thought. And I think to some degree, the same as Owen, I did see a proportion, a large proportion of the haemophiliac community as very weak. And I still think, to a degree, do today. I see haemophiliacs in two specific types. As the ones that have been wrapped up in cotton wool all their lives, by their parents, and never been allowed to do anything. So they've grown up exactly like that. And have actually, I don't know whether by chance or actually sought out partners that do the same, that carry on that mothering effect. And then there are haemophiliacs like myself, friends of mine, Owen, who get on. Who don't whinge and moan about the joint problems, their pain, their status. So I suppose all I thought was I was going to end up in a room with all them.

Sian:

Why did it change?

Mick:

For me, it changed that weekend. It was just a huge change. From going there on the Friday. Checking in, spending I think we were up until five, six o'clock in the morning, in the bar. And we just wouldn't go, and we kept drinking all night long. Until the meeting, on the Sunday. Where the idea of this meeting was to get more people involved in Birchgrove. Because it had grown so much, that the four original people could not manage it anymore. So we all went to this group, and volunteered to do different things. Now, I went from not wanting anybody to know whatsoever, and didn't want to talk to no namby-pamby girly haemo's, to putting my name down as the Birchgrove PR representative, wanting to talk on the radio talk shows and everything. So it was like a huge massive 'U' turn.

Sian:

And what was it? What made that 'U' turn?

Mick:

I'm not on my own. I'm not on my own. And I'm not mad. I'm not pathetic and stupid about thinking all the things I've been thinking about. And I think there were people worse off than me. There were people who were contemplating killing themselves. And for me, it wasn't the end of my world, when I was told I was HIV positive, my life has trickled on and progressed and progressed. So it's never, I've never been desperate through HIV, and I met people who had and were. Which made me feel strong.

Sian:

And Owen, for you, that moment, that difference?

Owen:

I think most of it was probably just a natural progression, and that the longer I lived with this, the more I realised that I had choices I could just give up, or I could do something about it.

Sian:

When you talked earlier, you said that you were very scared, and very frightened about what was going on. How significant has your involvement with the support groups been, to minimise that fear for you?

Owen:

Because I can talk with other people about the scary things that have happened to me, and we can laugh about them. And scary things still do happen to lots of us. We have scary stuff

going on with our bodies all the time. Even those of us who are on treatment. Haemophilia, HIV, Hepatitis 'C' maybe VCJD, they all affect your body in the weirdest most frightening ways. And some of us have had near death experiences more than once. And still have really scary times when they have to go for blood tests, and they don't know what's wrong with them, and all sorts of things. But when you get together with someone else and you talk about them and you can laugh about them, that's really helpful.

Sian:

Mick, your involvement in Birchgrove from that first weekend became quite significant in your life didn't it? Can you just talk about what Birchgrove is, and what you do get out of it?

Mick:

It was a self-help group. It was set up in the late eighties by positive haemophiliacs. Who decided to get together, because they felt that it was needed. And it sort of grew from there. In its heyday, I mean it was, as a sub group for the haemophilia community it was quite big. We had the national office, and four separate offices around the UK. And we produced, I can't remember whether it was a monthly newsletter at the time, or a quarterly. I think it's always been a quarterly newsletter, and that kept on until either last year or the year before, was the last one. And it's continuing to run now, but only online, on a website. And we periodically put updates that we know of on there.

Sian:

How significant was the information around your condition coming from Birchgrove, as opposed to maybe the hospital or the health care service?

Mick:

For me, and other people I've spoken to, we never used to get information from the haematology unit, the haemophilia unit. You never got it in them days and to an extent you don't get it now. They try and be more open, but they're not. So I think we gave a good range of everything around HIV and being a haemophiliac in the newsletter. Stuff that other haemophiliacs could understand, they could relate to. It was in English, instead of medical speak. And just a good all round source of information and support. Which you would not get, and still to this day I don't think, would get from the haemophilia unit.

Sian:

You Mick mentioned that you have these men only weekends, with people who have haemophilia and HIV. And I know that that's not always the weekends. The weekends are often with your partners, friends, sometimes there are parents and such like at the weekends. Are they, how different is the men's only weekend?

Mick:

I think I suppose it's not so different, than when any bunch of men get together. We're different. You know. We are different. There is no way... I reduce my swearing and my vulgarity and my obnoxiousness when I'm around my wife. Whereas when I'm with men, but specifically haemophilia men at the weekends, I let it all rip, I just say what I feel.

Sian:

Because it's quite interesting isn't it that your earlier comments about things being namby-pamby etc. People holding each other's hands and talking about how they feel, tends to be something that is often associated with something that women do, but men don't do. And I'm just wondering how much that impacted on how you originally felt about the whole idea of going to support groups, because they clearly would be all men. What about you Owen?

Owen:

Haemophilia itself mainly affects men. So it has been an issue of sharing it with the same people, then you're going to share it with men. However, also, one of the biggest problems certainly for straight men, and I'm a straight man, and talking about the problems I had when I was diagnosed, was about relationships with women. And talking to other straight men with haemophilia and HIV, I found the same. So, really one of our biggest concerns, was around relationships with women. And yet we were meeting up as men to talk about that, which may

or may not have been helpful, I don't know. However, I also talk to people's partners at weekends. And often I find that they're going 'hey go and tell my husband, what an arsehole he is'. I don't go over and say 'you're an arsehole'. But I talk to him about, we were talking earlier about how you learn from other people. And quite often I find that certainly the women who come with their guys with haemophilia, talk to some of us and say 'I wish you would tell my husband that, or my boyfriend that'. So we tell her husband or boyfriend that, whatever it might be. And they go 'Oh yeah'. So there's a dynamic going on there yeah.

Sian:

You must get lots of evaluations from people who go to these weekends, telling you how it's been and what they've got out of it. What are the sort of things that people say to you?

Owen:

What you've got to remember is, that a lot of the guys it happened to them when they were babies and it's all they've ever known. Some of them, everybody's reacted to that in a different way. But one of the things that still actually frightens me a bit, is I meet people who haven't spoken to anyone with haemophilia for years, and years and years, let alone someone with haemophilia and HIV and hepatitis 'C'. But by the end of the weekend, they've sat there and they've talked into the small hours of the morning. And we've had a laugh and we've been irreverent and we've been stupid. But at the same time, we've also talked to them about things, very simple things like HIV medication. A lot of the younger guys I talk to don't even know what tablets they're taking. Maybe that is a good thing, because they just take them and get on with their life, I don't know. But I'd find that quite scary. A lot of people still go to their haemophilia centre for their haemophilia care, their HIV care and the Hepatitis 'C' care. Which I think is madness. I think that what you need is good shared care, which is something you have to fight for in most Health Authorities. But there are a lot of things that a lot of people learn, and that is the sort of evaluation I get back from people, is they say 'my god I was scared of coming here, but I'm so glad I came here'.

Sian:

If I was to ask both of you then, on the whole subject of peer group support. Somebody who came along to you and said should I, or should I not be involved in something like that. What would you advice now be to people?

Owen:

I would say to anybody there is "what can you lose"? When I went along to my first positive weekend, I remember being quite worried about going. But I remember also thinking what have you got to lose. If you don't like it, you just go home. I mean it's not a major deal. You can go along and you can try it. If you don't like it, and it doesn't do anything for you, as long as you give it enough time, then go. But I know very few people over the years that I've been involved in attending and organising weekends, I've known very few people who have come along and left.

Sian:

On the whole concept of group involvement for any condition, why do you think.. there are a lot of groups out there, for people with chronic illnesses. What do you think a group can achieve that an individual might not be able to achieve? Mick?

Mick:

You tend not to believe one perspective. If you've got ten people saying the same thing, but you're actually thinking as well. Then you think 'well okay, it is real, and it's okay and it's acceptable, and it's normal, and I'm not going off the planet with this'. And plus it feels warmer. There is more people to share the burden with.

Sian:

And Owen, if I was to say to you, what is the success of these groups? You've seen them now over many many years, being very successful. And as you say people keep coming back and very few don't. Why?

Owen:

I don't know. I expect because up until now, up until people come to events or groups, they've been very isolated. And it's interesting as well, that there are people over the years that I've been involved, who have come and don't come anymore. Because they're getting on with their lives. And that really should be what it should be about as far as I'm concerned. We should be supporting people to get on with their lives.