# The Humanising Health and Care Podcast

**Episode 14 – Why don’t patients follow advice?**

Intro

Hello and welcome to the Humanising Health and Care podcast brought to you by the Point of Care Foundation. In this episode, Katie Campion, Head of the foundation’s Patient Experience programme, talks with Billy Mann and Claire Dawson about why it is we don't always follow the advice given by health care professionals. Thank you for downloading and we hope you enjoy.

Katie Campion

The Point of Care Foundation exists to humanise health and care, and I've always been really intrigued by what gets in the way of that and why that doesn't just happen. My name is Katie Campion and I'm the Patient Experience programme lead at the Point of Care Foundation. Now, as you may know, we run a number of programmes on patient experience, patient-centred quality improvement and how to use methods such as Experience-Based Codesign. And one of the things that's so powerful about genuine codesign is that you get to see both sides of the coin. Often the things that bother professionals are also bothering patients, but in a slightly different way. And something that I've heard quite recently on our programmes is professionals talking about frustration that patients don't do what's advised. Now, of course, that's completely normal, and I'm sure that everyone listening today has at some point not followed medical advice, whether that be something small like not completing a course of antibiotics, or maybe something a bit more punchy. So today we're going to look at the other side of that particular coin. Why do patients rebel? I'm joined by Billy and Clare, thank you for joining us, who both bring experiences of being patients. Billy I first met, quite a long time ago now, when I was working clinically as a neuro-physio in London. And Clare, we've worked together quite recently on a number of Experience-Based Codesign projects. Could you briefly introduce yourselves?

Billy Mann

Hi I'm Billy Mann, I live in the City of London and it'll be 10 years ago this year that I had a brain injury and I was taken to hospital. I was in severe stroke and things got worse and worse and worse and I was undergoing, I managed to get, I I got I I had surgery. And then I had rehab at the National Hospital and and then, I kind of rejoined the world in a wheelchair and then a walking frame and a walking stick. So I kind of getting into the rehab thing was, I was very lucky I got some intense rehab. When I was in hospital, I was I was Joe patient and, you know, I was supposed to do what I was told. And I didn't.

Katie

Clare can you introduce this?

Clare Dawson

Yeah sure, I’m Clare Dawson, I was diagnosed with a Ewings osteosarcoma when I was 17, so I went through quite intensive cancer treatment for about two or three years, which was pretty bleak. It was tough. And yeah, really took me away from the life that I was leading at that point. Was very isolating and. And lots of experience of inpatient care. I spent a lot of time in hospitals. After that, thankfully went into remission, but the treatment I’d had was so aggressive that it's kind of damaged my lungs to the extent that I now live with this progressive lung condition, which I have to manage, which also takes me in and out of hospital, but thankfully a bit less frequently than for the cancer treatment. But yeah, what it's meant is, is, you know, accepting that, living alongside an illness that you kind of know you have to manage regularly and trying to integrate that into your life in some way. And yeah, and absolutely, like Billy says, giving me lots of opportunities to not do what I'm told. There's lots of things I'm supposed to do to look after my lungs now and and it's yeah, it'll be interesting to talk about which of those I do and don't.

Katie

So Billy, can you tell us about a time when you rebelled, when did you not follow medical or professional advice?

Billy

Well, I I I do I don't. I mean, I'd like to think of myself as a rebel because it’s got quite a romantic image of, you know, baggage, stuff like that. So, but I'm really, I'm not very rebellious, I I I I. I argue a lot though. I'm not an obnoxious rebel, I'm more of a I I. like to sort of challenge people. So I would often. challenge my physio and OTs in hospital and say well, ‘Why are we doing this?’ And we basically, I would argue. I would argue against their expertise, and they’d have to justify themselves to me. I made myself the boss really. I suppose that's what I did. So one particular, you know, when you’ve had a brain injury, there's a lot of loss of control. And then as you’re progressing through therapy, you want to get back some of that control, so anything the physios and the OTs taught me during the day, I would be cheekily and sneakily doing it on my own when they weren't looking because you were not supposed to really get out of bed or anything like that and get into the wheelchair and wheel yourself around. Whereas I thought I'm gonna work out the best way to get out of bed on my own and into that wheelchair and start having a whizz around the ward and take a look at what everybody is doing and listening to conversations. So really, I shouldn't have been doing that that really. And when the nurses caught me doing that, they'd put me back and say, ‘Keep still. Keep still. Don’t move. Don’t move.’ And secretly I think some of the therapists really sort of liked that because it meant that I was seizing the opportunities for myself, and I was taking control of my own life and that kind of enablement is important.

Katie

I was going to ask you actually, how the professionals had responded to that? It's interesting.

Billy

Well, I was very, the team I was in at the National Hospital, they were very co-productive in the sense that there was five or six of us and we were all equal members of a team. We were very collaborative. And although, there was a key worker nominated, that's the physio and she she was notionally in charge. But really we were all working together and I became as interested in my therapists’ lives as they were investing their professional talents in my life. So, we kind of rubbed along as a sort of, you know, crazy crazy gang. And I loved it. I loved it, actually. It sounds a bit weird to say that when you're desperately ill, that you kind of enjoyed the experience, but I really thrived on it. It was, it was like being back playing football in the park when you were young.

Katie

What about you, Clare? Were you a rebellious teenager?

Clare

Oh no. I was absolutely, I, I think I was quite, uh, quite a square teenager. I worked hard at school; I did what I was told. I would very much follow the rules, which is quite interesting actually because I, obviously I was a teenager when I was diagnosed, and there was something that happened in that process of diagnosis and treatment that made me find my inner rebel for sure. Uhm, I think probably in all honesty, I hadn't had much to rebel against until that point. It was sort of, I had a very happy upbringing. You know it was, there weren't any real problems and so it was quite an insight that actually that first experience of suddenly, like Billy says, like the total lack of control over anything that brought it out of me. And I was someone, I wouldn't cast myself as a rebel at all, so I wonder if that's the case for lots of people, that that's what brings it out. That kind of, absolutely needing to find some element of control in the situation where everything just feels out of your control. So. I, I wasn’t until I was then.

Katie

And can you give me an example?

Clare Dawson

Yeah, I do remember being an inpatient and I wasn't allowed to walk around because my bloods were all over the place and I kept fainting, so I was in a wheelchair. And they said to me, you can go, you can try wheeling yourself down to the shop. Ah, but you didn't say which shop. So, I was in central London and decided to try going down Tottenham Court Road in a wheelchair with a drip bag that I had just taken off the stand and shoved it in the chair beside me and just thought, well, let’s just give it go. And it was a nightmare. I got really stuck because obviously I didn't have, well, I didn't have the energy to do it. And so yeah, that it was. I was not a kind overt arguing rebel, I was this quiet sneaky rebel. I'd say, ‘yeah, yeah, absolutely I'll do that’ and then go off and do something completely different and not follow the rules. So that’s kind of a distinct example, but I think even now when I look at the list of things I could be doing to the manage my lungs, I could be spending 4 hours a day doing physio, sitting on a nebulizer, doing postal drainage, there’s all these things that you can do to kind of prevent flare ups or infections and actually you know I I've chosen which fits, I do and don't. And actually, now I'm brave enough to tell my doctors that. I used to just say that I was doing everything when I wasn't. But that's been for me, a really pragmatic, it's not like a rebellious and doing it to stick two fingers up at illness or anything. It's been a really pragmatic decision rather than coming out of an emotional place, and because you know, in all honesty, that amount of time I'm not willing to give up that amount of time when you know you're not sure what your future is going to look like anyway. Kind of being right well, yes, I understand that might mean that things progress a bit quicker than they might have done. That's a decision I've made.

Billy

I was just going to ask Clare a question. Did you feel that you needed to take ownership of your condition?

Clare

Absolutely yeah. I mean, I think it's it's difficult, isn’t it, when you're first diagnosed with something, it's like such an alien world, isn't it? You don't speak the language, it's a new environment, and it's very difficult to feel ownership over a process when you don't understand the system that you're going through that process in. And it took me time, like I did become quite dependent and almost institutionalized at first. I was just like, you can do everything, you can look after me, you make decisions, and I’ll do it. But over time, I think it's so important, particularly if you’re living with a long term condition or side effects of a condition, I definitely needed to make that. Yeah, it needed to be something I’d decided on before I could buy into it.

Katie

Why, so you've talked about that you do some of the things to manage your lung condition now and not others. What, why? What's the decision there? Is it around time or is there anything else?

Clare

It's around time, it's around effectiveness. Like you know, which things are, it’s balancing up sort of the time taken versus the benefit got, you know. Cost, cost-benefit analysis. But also, side effects that they give me so, you know, if I sit on a nebulizer, it makes me cough all day and that takes it out of me and then I can't do bits of work. But you know, so it is a real kind of analysis in that sense, I guess. The things I feel that give me the most bang for my buck.

Katie

And how do you, you said now, you’re much more honest with professionals. You know, I'll do this, I'm not going to do that. How did, how is that received?

Clare

It's, it's interesting because it is different with different people. I think the team I, I'm lucky I've had one consultant looking after me for many years now, shout out to Professor Brown, and he you know, he's known me a long time, so he knows what I'm going to do and not. And because there's a relationship there, that feels much easier to be upfront and you know honest about what's going on. I found, yeah, interesting if I see new people, or sometimes physios as well because I think physio is, you know, that's their thing and they know how it works and it's kind of like it must be really frustrating to have someone who's just not willing to do everything that you say. So, sometimes there is an element of, kind of, of almost not understanding. So it really varies depending on who I'm seeing. You get the full gamet.

Katie

But it's that wider lens though isn't it? If, of taking a step back and seeing life, you know, you want to go and do things in your life. It's not just about the health condition.

Clare

Yeah, absolutely.

Katie

Billy, what about now? So, you talked about the acute hospital setting, being a bit of a rebel.

Billy

Yeah, I was going to pick up on something Clare said there. Because, I was thinking, I was thinking that the way I handled that was I kind of, I wanted to take ownership of the of the situation, and I did sneakily do lots of things. But what I also, I I I've very cunningly used my therapist as well. I cheated them into giving me tricks that, because I I basically said look, ‘when I go home I'm on my own. I'm on my own here now.’ I've got a, I’ve got a lifelong condition that isn't going to get better overnight. There is no tablets. There's no magic fix here. I've got to learn to live with a lifelong condition and I've got to enable myself to deal with it. So, I began to sort of, cheat them well, trick them into giving me information about how I can build therapy into my everyday life. So, I will empty the washing machine with my left, my disabled left hand for example. And I do a lot of things with my disabled side of my body now that I never did before. Simply because in the early stages they drummed that into me. They gave me repetition exercises to do and say when you get out, this will serve you well. So, I really, really wanted to build it into my ordinary life and not just follow rules.

Katie

But I'm intrigued that you used the word ‘tricked’. ‘I tricked them into…’ Tell me more than that.

Billy

Yeah, well, I think there's a medicalisation of conditions. Brain injury is a strange one because it's, you know, it's part medical. But it's, also there's a whole load of other stuff. There's a whole lot of psychology attached to it, it's a, it's different. And long term conditions I sure are different to short term conditions where you know the body will repair itself. My body isn't going to repair itself in the way that it was before I had a stroke. It's, it is what it is now. I kind of, I was actually honest with them and said look, I've got so, I did need to know how to get out of the bath. I need to know how to get out, you know so it's stuff like that. I was trying to replicate my everyday life while I was in hospital with these experts. And so, I was just saying look this is what. I kind of took charge of this situation, I became my own director in that sense.

Katie

So, then my next question is, why? And we’ve talked about this already. But thinking more broadly about patients in general and their families and friends, why do people rebel?

Clare

Uhm, well. I mean, I'd say. I mean, there's so there's a lot of reasons, and I think broadly you can probably split them into very practical things. You know, time, not having the time to do it. Sometimes not the money, you know financially people get hit really hard when they live with chronic illness. And if going to a particular therapy means travelling and you know like, it can be as much as that. Energy. You know, if you haven't got, if you've got fatigue, just getting yourself up and making sure you've eaten three times a day can be a real challenge. So then trying to fit in exercise or something that to you feels like a real energy drainer can be really tough. So there are lots of practical reasons. I think the psychological ones are sometimes more interesting, like the sort of, and like that idea of rebellion. Like do you see yourself as a rebel? Do you like being told what to do or not and then taking things from authority figures, how do you deal with authority figures? Are you good at that or not? That can be a reason? Then I think there's also an element of, for me like, acceptance around your condition. I know for a long time I didn't. I didn't look after my lungs at all. I didn't take the medication properly. I didn't do. And it was a bit of a head in the sand like this isn't happening. I'm not doing, if I start doing everything I'm supposed to do, then that's a real acknowledgement of what's going on. And I just wasn't ready and it was scary. You know that idea of you're going to be living with something forever. That is a big deal. And maybe if I just go on with today and ignore that, it'll you know and and you know with my condition it's almost possible to do that because it is a gradual decline rather than something that really impacts me on a day-to-day on a good day. I think that you know so that can all be about fear as well. Fears about the future and not having had those conversations with people. And I think it's just why it's so important to talk to people about what your fears and anxieties are, what what's, what have you got in your head as your worst-case scenario. Because if you're holding all that in, it can be a real drive to just put your head in the sand, not talk about it, not think about it. And not engage with what's good for you.

Katie

I think health professionals can quite often see that as a bit of a can of worms – on both sides actually. It’s quite a big thing to open up and have the skills and courage to kind of lean into that. But it, it can really unclog things can’t it. Billy?

Billy

I think it can, yeah, but I think also, if you're a patient and you work in partnership with your therapists and your health care professionals, then if, if you're able to establish a partnership, it’s more, it, it becomes more valuable to both parties. And it, it just it, it's more meaningful. It's a more meaningful journey for both the healthcare professional and the patients because it means that you, you’re both invested in this thing. And so there’s, there's a high level of commitment there. Turning that around. that's, that's a that is a mindset. Clare is right, having that as a mindset, people often with illnesses think, ‘Well the doctors are there to cure me. The healthcare professionals are meant to make me good again.’ But some illnesses are just not like that. And also, I just like I mean healthcare professionals vary a lot as well. So, you can normally tell whether you are going to be able to make a partnership work with somebody – just like any other situation. A relationship with a healthcare professional is just like any other version. You know, you have to see, is this going to work? Do we both want it what it, want do we want? And so there's a whole load of stuff there that you don't really take into account, initially, because it is often seen by the patient as being a transaction. That the healthcare professional provides you with a solution to your problem, and it really, it’s a lot more complex than that.

Katie

So how do you know if the relationship is going to work?

Billy Man

If, I can normally tell because I'm very argumentative… I'm not argumentative. I've always been a… If I see a hole, I'll dive down it. I'm like a sort of, you know, naughty schoolboy in that sense. So, I've always been like that. I've always been, ‘oh what happens if you press that button.’ So, I will do that. I am I'm like, let's see what happens. What can possibly go wrong here? Bang. So, I've done that, so I'm constantly challenging. I'm constantly looking for new ways, constantly experimenting, saying, why don't we try it like this? When we try it like this with physios. I remember several occasions that I could not get into a certain yoga position called ‘the cat’. The physio just became so exasperated and eventually, but, eventually she found a way for me to get into this cat position and it worked. So, by me saying I wasn't just whinging, saying I can't do it, I can't do it. I'm saying, ‘I can't feel my shoulder blades the way you want me to feel them.’ So you know, what can we do next? What can we do next? And we kept going and kept going and kept going until we found a way.

Katie

So how do you know what would tell you that the relationship isn't going to work?

Billy

Someone who’s going to be completely bossy and managerial. I will just think sod off. There's no chance of a productive relationship here.

Clare

I'm with you on that one Billy. For me, it's also about like the kind of veneer of professionalism. Like, I can't when you've got lots of jargon, when you feel like just another patient, that's that's, you know, if you're dealing with this your whole life, you can very easily feel that you're on a conveyor belt going through a system and that is absolutely disempowering. You know, I just, I know if a doctor was going to come in and, you know, rather than say this is what you need to do XYZ, very informal and cold and distant. Rather than if someone came in and went, ‘Oh well, this is all a bit rubbish for you, isn't it? How are you doing?’ That would just, it's just authenticity I think for me. And I think also another thing as well, is kind of honouring the experience that the patient has. So, you've got someone who's lived with the condition for 25 years and has grown up with it, you know, I'd hope that you'd know that they have a fair amount of expertise. And so kind of rebalancing those positions of expert and professional and patient, uhm, kind of acknowledging the amount of expertise they have on what they've been through. Because it's teaching your grandmother to suck eggs if you start telling me ‘well physio could help.’ I'm like, ‘ah yeah I am aware.’ I think when you have those good relationships, what happens is you know you, you know a bit more about the wider, the holistic experience the person life what, what, what's important to them, what's meaningful to them and therefore all your recommendations about what could help are grounded in their reality, not in yours. It's not sort of like I know from my textbook that this will help. It's like, I thought about this. I thought about you in your context, and actually I think this might work. You know, give it a go, but without holding onto it too tightly like this is the solution. Give it a go and then we can chat and see if it has. And it's that sort of, exactly what Billy's been saying, it's like an equal partnership.

Katie

So, to finish off, imagine you've got this healthcare professional, they're working in a busy GP practise, for example, seeing lots of patients – a fairly short space of time that they're seeing people. And one of the things that I've heard recently over the last month is frustration when someone comes with a problem and you offer them advice and they don't take it. And then they might come again with the same kind of problem. So in that type of situation what would you advise healthcare professionals to do or to be like, to get that relationship, to have that partnership and to develop that trust?

Billy

It's basically, you know it, it comes from a down to the partnership. How can I make a partnership with this person? So if Katie, you started telling me to do various things, I'd say (and I I, really it wasn't working for me), I’d say, ‘let's work, let's find a way that we can make this work, shall we?’ So I try, I I I. kind of use that that kind of language and I'll say, ‘let's do this together.’ I often do it with other people with brain injury, if they, if they are reluctant to do something, I'll say, well, let's do it together. Doing it together is important in my case. There’s a lot in that. You can get a lot from other people. So regardless of that health care professionals, or whether they’re fellow patients, then you know form partnerships. Is my advice.

Clare

Yeah, absolutely. I think for me it's kind of maybe about acknowledging the frustrations and what you're living with so if you’re going in, and you know I I had this experience of saying, you need to exercise more and I'd be like ok, well that's a very vague description of you know when I feel like I can't breathe walking upstairs like what does that mean? And I'd freak out and wouldn't do it at all. And if someone had said to me, ‘this must be really frustrating. It must be scary when you feel you can't breathe. What is it about that experience that puts you off?’ You know like well and also kind of there is something about the sort of shared humanity where you know nobody does what they're told all the time. And I think most people have a luxury of being able to skip corners with their health. Or, you know, eat what's not good for them. Or drink a little bit too much and it's almost like this expectation that when you're living with illness, you should be this perfect person who does everything that's right for them all the time. And I think maybe just acknowledging that going look, we all do stuff that's not great. Ideally, this might, this might work for you but it's obviously not. So, let's chat about that rather than telling you off or being disappointed, or just giving you the same thing again and telling you to go away and come back in six weeks’ time. Obviously, this isn't working. Let's have a chat about it.

Billy

I used to say to my team, let's make this fun. So, I'd want us to all be laughing together doing, trying to fix me in some way. I'd want us to have a good laugh. I want to have a good time together. I want it to be, you know. That's fine.

Katie

Yeah, it sounds like you both bring quite a lot of experience to your healthcare interactions now, so I thought I'd asked my last question, but now this is my last question. What would you advise patients, so you know people that maybe, maybe they've just had a stroke, or maybe they've just had a diagnosis of something. What would you advise that people bring as patients to those healthcare relationships?

Clare

It’s really tricky because it's worth acknowledging that when that has just happened, you, well I didn't, speak for myself, I didn't feel like I had much to bring. I was so kind of physically, you know, you have to dig really deep. But I think it's maybe about giving yourself the space to acknowledge what you bring, like the skills you already have. Like you will have lived a life and done amazing things and achieved stuff. And don't forget that, you know, like you're not reduced to just being your diagnosis. You come with a whole wealth of experience and background and context. And I think it's really hard to advocate for yourself in those positions. But if you can, communicate that to the people looking after you, like this is what I'm good at. This is what I like. This is what I don't be. B brave because it doesn't feel OK sometimes to say those things and be a bit demanding and you know, shout out for yourself. I think that's really important acknowledging what you've, what you bring to the table.

Billy

Be honest. Be honest with yourself first and then you can be honest with your healthcare professionals. And I mean, really don't be afraid of making a mess of things. Just try it. Don't be afraid of making a mess. Don't be afraid of exposing your vulnerability because it you know; they will respond to that. They want, they want to be, they want to get a big kick out of it as well.

Katie

Brilliant, thank you both so much for joining me. It's been really, really interesting and yeah, that's our conversation about why patients rebel.

Outro

Thank you for listening to this episode of the Humanising Health and Care podcast. You can find all episodes and more on our website at [www.pointofcarefoundation.org.uk](http://www.pointofcarefoundation.org.uk/) and be sure to subscribe wherever you listen and follow us on Twitter to be notified when our next episode is available.

Thank you.