



Who Says You Can't Podcasts Series 2 Episode 2: Jessica Kellgren-Fozard

[Music]

Jessica: [00:00:02] I think that the word 'disabled' is a wonderful word, and for me it is incredibly positive, because I would not have been able to get through the end of school and university and really my life without being labelled as disabled, because all it did was give me access to the help that I needed. So, for me, I think it's something that I should be really proud of, in the same way that like I'm proud of being gay, like it's great, it's just a part of me, it's a great part of me, [00:00:31] it's just a thing to do with me, and I don't need to feel ashamed of it or embarrassed by it or think that it's inherently negative.

Rick: Hello, and welcome to Series 2 of *Who Says You Can't*, the podcast from EE that celebrates those who fly in the face of convention. I'm Rick Edwards, and in this new series I'll be talking to people who didn't wait for an invite to create their dreams, people who have used all the digital tools at their disposal to make it and who took 'You can't do that' as a challenge and just did it anyway. Each guest has handed over their phone for me to have a good old look through, and I'll be asking them questions based on what I dig up. If you want to get a peak at what I find you can see them on EE's YouTube channel now. Today's guest is YouTuber, Jessica Kellgren-Fozard, bringing invisible disabilities into the light. Who says you can't? Jessica, hello.

Jessica: [00:01:26] Hello.

Rick: Thanks very much for joining me. How are you?

Jessica: [00:01:29] I'm very good. Thank you for having me on my first ever podcast.

Rick: First ever podcast?

Jessica: [00:01:33] Yeah.

Rick: I'm going to be gentle.

Jessica: [00:01:34] Okay, thank you.

Rick: Although I am also going to be a bit probing.

Jessica: [00:01:37] Yes.



Rick: But you know that, don't you.

Jessica: [00:01:39] I am aware of how this is going to work. This is very scary for me, I must admit.

Rick: You've unlocked your phone so that I can have a look through it.

Jessica: [00:01:47] Just going to hand you all my details, it's fine.

Rick: It's been very interesting looking through your life, very interesting.

Jessica: [00:01:53] It's a bit terrifying, yeah.

Rick: There's plenty to talk about, that's the main thing.

Jessica: [00:01:58] I mean, that's at least a good thing.

Rick: Just worth mentioning to the listeners, or indeed if you're watching this on a video of some description, that you are deaf, so we've also got your interpreter, Ruthanne, in the room here. Hello, Ruthanne. So your YouTube profile describes you as a deaf YouTuber who makes videos about my life with disabilities and chronic illness in a positive, uplifting way, LGBTQ+ awareness and vintage fashion. There's a lot in there.

Jessica: [00:02:28] Yeah, there are also dogs.

Rick: And dogs.

Jessica: [00:02:31] And dogs.

Rick: And dogs.

Jessica: [00:02:32] Forgot to mention that one.

Rick: How high in the mix are dogs?

Jessica: [00:02:35] Oh I'd say really that they're the stars of the show, I'm just a special guest really, like I'm in every video—

Rick: But it's about the dogs.



- Jessica: [00:02:41] – but people watch for them, let’s be honest.
- Rick: So how would you describe your job then?
- Jessica: [00:02:46] What a question! Well, I guess I’m a YouTuber, which is a job description that I have to give at things like banks, and they go ‘A what now, sorry?’ ‘I make videos, two a week, on a range of different topics, and I have to do absolutely everything to make them happen’. Being a YouTuber is basically like making a TV show twice a week but you’re every single role. I have a great back of house production assistant, Clara, who works with me, she’s fabulous.
- Rick: Oh she gets a mention.
- Jessica: [00:03:17] She gets a mention, she gets a credit too, yeah. The dogs there, added cuteness, that would be their role, but yeah. So when you’re a YouTuber you’re doing everything, you’re creating the idea for the video, you’re producing the video, directing the video, often filming the video, presenting the video, editing the video, marketing the video.
- Rick: So how many social media channels are you trying to juggle at any one time?
- Jessica: [00:03:40] I keep it to a quite conservative four, I’ve got my YouTube, which is my main thing, that’s what I spend most of my time on, Instagram, which I spend way more time on than I should, and then Twitter obviously, which is a great way to keep people updated about what’s going on, and Facebook, where there is a small but dedicated following of people who dislike other social medias.
- Rick: So do you tailor your output to each channel then?
- Jessica: [00:04:07] Yes, yeah, I suppose so. I forgot to say, I actually have two Instagrams, slash three, because I have my own one, my wife and I have one together, and then our dogs have one.
- Rick: Of course they do.
- Jessica: [00:04:21] I mean, I told you, they’re very important.
- Rick: Hang on, are they not managing their own account yet?
- Jessica: [00:04:25] I know, so rude.



- Rick: Get them on that.
- Jessica: [00:04:27] They make me do it.
- Rick: They're just lazy dogs, honestly.
- Jessica: [00:04:30] I know. Yeah, so I definitely do different things. On my personal Instagram I'll obviously talk more about vintage fashion and chronic illness and disabilities and that kind of thing, and then on the one I share with my wife it's obviously more LGBTQ+ focused, but also quite heavily talking about what it's like to be in a differently abled relationship, because my wife is able bodied and hearing and not any of the things that I am, [00:05:01] except for gay, obviously, fortunately.
- Rick: That is fortunate.
- Jessica: [00:05:04] It would be really tragic if we weren't, but yeah. So there we kind of talk a lot about what it's like to be married to someone who is deaf or someone who is disabled, because a lot of our followers are either people who'd never considered dating someone who has a different type of body before or people who themselves had grown up, like I did, with a disability, and just thought 'No one's ever going to love me for because I'm such a difficult burden'. [00:05:35] I was amazed by my lovely wife when she turned up, but, you know, there are wonderful people out there in the world and it's nice to give people a bit of hope I guess that I wish I had had when I was younger.
- Rick: So you posted a photo, the 10 year challenge, so you in 2009 to you in 2019. What's changed? It looks like quite a lot has changed.
- Jessica: [00:06:01] I like that this is a podcast and therefore we're going to have to describe these photos.
- Rick: Yeah. Well actually people will be able to click and see them, so we've thought about this.
- Jessica: [00:06:10] Oh good job.
- Rick: It's very clever.
- Jessica: [00:06:12] Very good job.



Rick: Thank you, thank you.

Jessica: [00:06:13] Sure. So in my 10 year challenge, in 2009 I was very, very ill, I was at the lowest weight I've ever been, not ever, obviously I was born, I wasn't this size.

Rick: You mean in your adult life, yeah.

Jessica: [00:06:29] Didn't just walk out this way. I was only six stone at the time of this photo –

Rick: Wow.

Jessica: [00:06:35] – and I was having all types of different problems that were going on, because basically I have a genetic disability, I have two of them, which is amazing, like one from each parent, it just hadn't been managed properly, hadn't been dealt with, I wasn't getting the care that I needed to be able to be on top of my disabilities and managing them myself. I'd gone away to university for the first time and left home, and I just wasn't able to cope at all. [00:07:05] Fortunately what changed after this, it was a very long, uphill battle to be able to fight to get the care that I really needed and to see the doctors who actually were the specialists who knew what to do about my specific condition and how to treat it. Now I think I'm looking good, if I'm allowed to say?

Rick: I think you are, absolutely.

Jessica: [00:07:26] Thanks, thanks, looking great, because I've managed to just find the right care and the right medications that work for me, and also, at the time I'd gone through about six different dieticians in the hospital who all gave me differing advice, and it's taken me 10 years to kind of work out my own, what I can and can't eat, what my body can cope with, what I can't cope with. It's been a long, uphill battle, but it's been a successful one.

Rick: So at what stage in that 10 years then did you decide to start YouTubing?

Jessica: [00:08:03] Ooh, really not that long ago. I've only actually been doing YouTube for three and a half years now, because I worked for a local TV station before that. I've always wanted to work in film and television, just sort of telling stories, I've always been a storyteller, and then I met my wonderful wife, we got married, and she said 'You know, I'll give you six months, why



don't you just try doing YouTube, just do your own thing anyway?' I was like 'Okay, great, I will'. [00:08:29] Fortunately it did actually work out quite well, because otherwise I think my wife would be like 'Now you get a regular job'.

Rick: Yeah, 'Now back to it'.

Jessica: [00:08:38] Great, back to the –

Rick: 'You've had your chance'.

Jessica: [00:08:40] Yeah. Fortunately, no, it worked out, it's okay.

Rick: Do you get a lot of people asking you, or saying to you rather, 'You don't look disabled'?

Jessica: [00:08:51] Yeah, yeah.

Rick: That must be a favourite.

Jessica: [00:08:53] Oh all the time, it's so great, it's so great. Yeah, so I'm what's called ... I have an invisible disability, I'm invisibly disabled because you can't necessarily see what's wrong with me just by looking at me, which I kind of take issue with because when can you ever really see stuff, like you can't, you don't know what's going on inside someone else's body. So sometimes I'll be using a power chair or a wheelchair, and then I guess I'm more visibly disabled, and the way people treat you is kind of amazingly different.

Rick: In what way?

Jessica: [00:09:27] So just things, little things like being able to ... they'll open a door for you or get out your way. Actually they don't, god, you go along in a power chair people will be very careful not to look at you, very careful not to make eye contact, I think it's because they don't want to stare at you, but then they end up not looking at you and just kind of blanking you, and then you just drive into them because they won't get out the way, like 'What are you doing? It's fine, just look at me, just look down', you feel like 'Oh excuse me, move out the way'.

Rick: So where has that come from though, is that people being like nervous about doing the wrong thing –

Jessica: [00:10:05] Yeah.



- Rick: – or sort of overcompensating in some way?
- Jessica: [00:10:07] So I have this whole theory that it's a childhood phobia that we put into our children.
- Rick: Oh wow.
- Jessica: [00:10:13] Yeah, we're going to get in deep now.
- Rick: That is deep, yeah.
- Jessica: [00:10:16] We're going to get deep.
- Rick: Here we go.
- Jessica: [00:10:18] So the thing is, if you are, for example, on a bus in a wheelchair and there's a small child that looks over and goes 'Oh mommy, that lady's in a buggy too'. Now my response is that I'm super-happy about that, that child is just curious, they want to know what's going on, and so often the parent will be like 'Oh no, shhh, don't talk about it. No, don't look, don't look', and it's putting into this child this sense that this is something wrong, that this is something that they should be afraid of or that they shouldn't be able to talk about, [00:10:49] and it puts a little bit of fear into them, because you've just given them the same response as if they've tried to walk out into traffic, you know. Then, as they grow up, they're internalising and learning that shame, so they're thinking 'Ooh, this is something that I shouldn't be looking at, I shouldn't be talking about, this is something that's awkward and weird', whereas I would much prefer it if parents just let their child come up and I'd be like 'Hi, this is a wheelchair', they'd be like 'Why are you in a wheelchair?', I'm like 'Oh well, I'll tell you all about it, child'. [00:11:21] I think it's much better to talk about things, and that's one of the great things that we have now with social media, is that we're getting the representation of real, everyday lives that we weren't seeing in our mainstream TV shows, for instance. 20% of the UK population has a disability, do 20% of the characters on TV have a disability?
- Rick: I know the answer to that, no.
- Jessica: [00:11:43] Congrats, the answer is indeed no. Yeah, so it's very difficult for us then to be learning and to be talking about these things if we're not seeing them represented. 40% of people in the UK say that they've never met



someone with a disability.

Rick: And that maths doesn't add up, does it.

Jessica: [00:12:01] That does not add up at all, no, whereas if we're looking at things like social media people are being much more open, they're talking about it, you know, whether it's a chronic illness or it's a mental health problem or it's a physical difficulty, we're talking about it, we're seeing it represented, and it's a much easier way to start a conversation, because you're not having to say 'Am I wrong?', you can watch someone's video and it's a kind of educational thing. I like to think that what I do is called soft activism.

Rick: What do you mean by that?

Jessica: [00:12:32] Well it's just my belief that people are always going to be more open to learning about things if, instead of like shouting in their face going 'You have this wrong belief, this is why you're wrong', instead I find it much easier to go 'This is why I think this way, it may be different to the way you think and that's fine, but this is just why I think this, and maybe here are some really good reasons as to why you might possibly want to think like this in the future, but hey, you know, if you agree with me that's wonderful, but if you don't it's fine'.

Rick: Gentle powers of persuasion.

Jessica: [00:13:04] Yeah, I never –

Rick: Rather than dogmatic shouting.

Jessica: [00:13:06] I'm not going to yell at someone and tell them that they are wrong, I'm just going to say 'Here is why I think that this belief is right'. The real kind of crux of why I make videos about the things that I talk about is that when I was a teenager I was really, really ill, so when I paralysed my arms and I got took to hospital and I had this hospital procedure that went wrong and drained out all my spinal fluid, that was a whole drama, and I had to be on bed rest –

Rick: Is that what's affected your memory?

Jessica: [00:13:35] Yeah, yeah, yeah. I had to be on bed rest for two years, so I couldn't have any light, I couldn't have any sound, I couldn't have touch even, was excruciatingly painful. So I was essentially just lying by myself for two



years, having to keep myself entertained with my little stories, and one of the things that really kept me going was the thought that I couldn't be the only one in this position, there must be other people out there who were going through this, and I thought 'You know what, if I get out, if I make it to the other side, [00:14:06] I want to be able to turn around and to help those people, to offer them a hand and to say "Look, you're going to be able to make it, you can do this, and you're not alone"'. Because often being disabled is an incredibly isolating experience, like it is for me, I leave the house once a week, it's very exciting, but the rest of the time it is very isolating, I'm just in my own house, knocking around with my dogs and my wife and the people who work there, which is lovely but lonely.

[00:14:36] So for me YouTube is a way to connect with people who were in the same place that I was, who are in a place that I am, who also aren't able to see a lot of people, of connection, free represented when they're looking on TV or in films, and it's also a way to be able to educate people who have no experience of this situation, who have never thought about 'Yeah, there was that kid in my class, and then they just stopped coming to school and I haven't seen them for six months, [00:15:08] I wonder if they're okay?', because I was that kid who just dropped out of life, it felt like. I feel like I said no to being able to go to a party three times and that was it, my school friends left me. So I need to be able to find a way to talk to those kids and say 'You're not alone and it's going to get better'.

Rick: Just a quick interruption to the podcast to say that *Who Says You Can't* is brought to you by EE, who have been busy rolling out 5G in more places than any other network. Want to connect near instantly to streams? Want to download films in seconds? Want me to carry on with the podcasts? Yeah, that's fair enough.

Your *Straws* video –

Jessica: [00:15:50] Don't take our straws.

Rick: – was really interesting.

Jessica: [00:15:52] Thank you.

Rick: It was really interesting.

Jessica: [00:15:53] Thank you very much.



- Rick: Because I think I just immediately, as soon as I heard all the negative attention around plastic straws and, you know, the sort of blue planet stuff, you were like 'Yeah'.
- Jessica: [00:16:02] You were like 'Who needs plastic straws?'
- Rick: But it's true, I just hadn't, and I felt like an idiot as soon as I watched your video explaining why they're so important and the fact that they were first ... you know, bendy, plastic straws were first developed for medical reasons and used in hospitals, I was just like 'Ah, yeah, yeah', and really the penny dropped for me.
- Jessica: [00:16:23] Did it?
- Rick: Yeah, so thank you.
- Jessica: [00:16:24] You're very welcome. There you go, go watch that video if you're confused about straws.
- Rick: It's a good video and Jessica explains why they are vital for some people and we shouldn't just get rid of them without thinking about that.
- Jessica: [00:16:36] You see, the thing with straws is that people who don't need them think that they are an unnecessary item, 'Why does anyone actually need a straw? You don't need a straw, you've just got to learn to be better at holding your drinks?', but for many people that's not possible. What do you do if you're lying on the floor, as I have to do a lot of the time? You need a straw to be able to drink, right? Or if you're thinking of people who have got very bad control of their hands, straws, very useful, very helpful. [00:17:06] A lot of people with learning disabilities die from aspirating on liquids.
- Rick: Is that right?
- Jessica: [00:17:12] Yeah, when, if you think about it, a straw could have just helped with that. So people who don't need them think 'Oh, why do you need it?', in the same way that people can get very angry about seeing pre-diced vegetables in the supermarket, 'Why is there an orange that's already been peeled, how stupid is that? No one needs that', and they're only thinking that because they don't need it, but there are many people who do. A lot of people with disabilities don't have the dexterity to be able to cut up a vegetable themselves, [00:17:42] don't have the strength to be able to do it, people who have got very low control of their fingers, might not be able to



peel an orange, but they still want to eat a bloody orange, you know. I have a friend with cerebral palsy who, when she wants a snack from the supermarket, she doesn't want to have to buy something that is super unhealthy that comes in small pieces, she wants a piece of fruit, but how is she going to be able to get that piece of fruit? It needs to be something that's pre-cut up, like an apple, something that's pre-peeled, like an orange, [00:18:12] and so many people just have different needs and you really don't realise until you're in that situation or you know someone who is.

[00:18:19] I forgot to say, but actually one of the reasons I started my YouTube was because I was sort of shown on the local TV channel as being 'the disabled presenter', and someone left me this comment on my Instagram that was like 'How dare you call yourself disabled, you're a disgrace to the disabled community, you have no visibly obvious problems, you can't use the word "disabled"', which I always think, whenever someone's like 'You're not disabled enough', I'm like 'Cool, come and look after me for a week, you just volunteered, right?'

Rick: It's such a strange position to take, 'You're not disabled enough'.

Jessica: [00:18:57] Please tell me where this bar is, right?

Rick: I know, who's setting this bar, but more to the point, why, like why?

Jessica: [00:19:04] Indeed. I can't stand it when people create this hierarchy of disability, it's called, where there's this idea that certain disabilities, certain types of problems are more deserving than others.

Rick: Sort of trump others.

Jessica: [00:19:16] Yeah, yeah, and then there are like those at the bottom. Unfortunately it feels a lot like mental health problems kind of get dumped in at the bottom and they don't get the attention that they need, and obviously they're also invisible. So even though I don't have any mental illnesses myself I always try and make reference to it on my channel when I'm talking about disabilities and chronic illness, to say 'There are things with your body that are not visible, that can set you back just as much as something that is completely visible', [00:19:49] and often more so because of the way that the rest of the world reacts to you. Like if you're going into a disabled toilet, I've had people stop me and be like 'Erm, that's a disabled toilet, you're not actually allowed to go in there', and I'm like 'This is the one time I wish that we had a disabled card, so I could just pull it out and be like "Excuse me, I think you'll find this is my disabled card"'.



- Rick: They could have it on a necklace, like 'Er, check this out'.
- Jessica: [00:20:13] 'Excuse me, excuse me'. Yeah, so I love that things, like a lot of restaurants and airports, public spaces now, have 'Not every disability is visible' written on the toilet doors and not just a symbol of a person in a wheelchair, because there are so many reasons relating to disability that someone would need to use a disabled bathroom that do not relate to being in a wheelchair.
- Rick: It's a very narrow definition of disabled, isn't it.
- Jessica: [00:20:38] It is, it is, yeah. It's not helpful.
- Rick: Is it nice now, that with the YouTube channel, you have these kind of nicely filmed, edited, presented answers to a lot of the questions that people ask you?
- Jessica: [00:20:53] Yes.
- Rick: So you can just say 'Great question, get on the YouTube channel'?
- Jessica: [00:20:57] Yeah, yeah. If someone sends me a question on Twitter I'm like 'Yeah, I have a video on that', but also what I try to do is to create videos that I know people will be able to send to other people, because quite often it is very difficult to have the words for yourself, and especially if you're quite young, to be able to say 'This is what I'm feeling and this is what I'm going through', because I know myself, I wasn't diagnosed until I was 17, and that was a very long time of trying to explain to someone, 'This is what I'm feeling and this is what I'm going through', [00:21:26] and I was living with chronic pain and chronic fatigue, and I'm in excruciating ... like it hurts so much all the time, and people don't believe that children can be in pain. So now what I do is I'll make videos that try and explain different symptoms or different conditions, that someone can then take and send to their friend group or send to their aunt and be like 'No, this is how I feel', and I'm there to give the words that maybe they find it very difficult to voice.
- Rick: So not diagnosed with chronic fatigue syndrome until you were 17?
- Jessica: [00:21:56] Yeah, yeah. So I wasn't diagnosed with either of my genetic conditions until over the age of 17, so everyone just thought I was really lazy and a whiner. So one of my conditions affects my nerves in my body and it



means that I have no myelin sheath, like I have holes in my myelin sheath, which means that my nerve underneath is therefore sort of –

Rick: Exposed.

Jessica: [00:22:20] – exposed, out to the world and is very vulnerable. So I can paralyse bits of myself, so when I was 17 I paralysed both of my arms for a year and a half, which is the kind of big thing, that people went ‘Oh, maybe there’s actually something wrong with that kid’.

Rick: Yeah, that’s a clue, isn’t it.

Jessica: [00:22:35] Yeah, but it also means that my nerves will react differently to things. Cold feels like someone’s flaying me alive, so as a small child I’d be like ‘I don’t want to go out, it’s cold outside’, and people would be ‘It’s not that bad, it’s fine’, but I’m thinking ‘No, no, it’s really terrible’, and I wouldn’t be able to voice and there was a real difficulty in getting adults to take me seriously, and then finally being able to be like ‘Look, it’s genetic, it’s in my genes, there’s a test, it says yes’.

Rick: I imagine there’s a feeling of not wanting these sort of labels to define you, but also these labels are useful?

Jessica: [00:23:16] Yeah. So I have a real thing with labels, where I think that the word ‘disabled’ is a wonderful word, and for me it is incredibly positive, because I would not have been able to get through the end of school and university and really my life without being labelled as disabled, because all it did was give me access to the help that I needed. So for me, I think it’s something that I should be really proud of, in the same way that I’m proud of being gay, [00:23:45] like it’s great, it’s just a part of me, it’s a great part of me, it’s just a thing to do with me, and I don’t need to feel ashamed of it or embarrassed by it or think that it’s inherently negative.

Rick: How does it affect your day-to-day life and how useful is tech in helping you, because I was looking at your calendar stuff and there’s lots of stuff, remind us of the medical, like pills and things like this?

Jessica: [00:24:14] So it affects my day-to-day life in obvious ways, like when it comes to exhaustion and fatigue, I find things like leaving the house is even quite difficult, I tend to get out the house about once a week, so you’re very welcome –



- Rick: Oh thank you, yes, thank you.
- Jessica: [00:24:29] – for my trip out of the week, come to see you. So yeah, I’m often, yes, at home, I have some very stylish pyjamas that I like to wear around, some lovely silk nightgowns, all of that, because just getting dressed, it’s a lot of effort. There are a lot of days where just having a bath would be an excessive amount of energy for me, probably two days a week I’m just in bed, and I get to work from bed, fortunately, [00:24:59] because I have a job that allows me to work from bed, but physically that’s my limit, and then that has knock-on effects mentally, so I might not be able to think my thoughts fully and put together thoughts because there’s just that ... if you can imagine, have you ever run a marathon?
- Rick: No, no, no.
- Jessica: [00:25:19] Okay, what’s the most physically exhausted you’ve ever been?
- Rick: I played in a five-a-side tournament last summer on a much bigger pitch than I’d played on for a long time, and at the end of that, I mean, I thought I was dying.
- Jessica: [00:25:31] Did you have that moment where you’re like lying on the floor and you cannot think your thoughts?
- Rick: Yes.
- Jessica: [00:25:35] You’re like ‘No, no, thought, no, what? Who, who am I?’
- Rick: Yeah, just like quiet, some quiet.
- Jessica: [00:25:39] ‘What’s going on?’
- Rick: Yes.
- Jessica: [00:25:40] ‘Where am I?’ So unclear. That’s me like half the week, just like ‘I do not know what’s going on and where I am’.
- Rick: There’s actually a really good video of yours, the one where you have the brain fog, you call it, where you’ve done it, when you’re in quite a bad state, and I thought it was fantastic because I’d never ... it’s interesting, I think I’d heard people talk about that before but not whilst experiencing it.



Jessica: [00:26:07] Yeah, it's really difficult to film obviously when I'm having my really low moments, not just because it's like 'Oh, do I want to show this?', but more because you have to remember to put the camera there and to turn it on, and sometimes I stare at it and I'm like 'I don't even remember what record is any more, which button is record, what is going on? Wait, what am I doing? I don't know, I'm just going to go to sleep again, it's fine'. It's a bit much.
[00:26:35] Then there are kind of other things, other ways that it affects me, so I've got chronic pain because of my nerve condition but also because I have a connective tissue issue, so I'm very flexible.

Rick: Ooh, that's –

Jessica: [00:26:48] Oh yeah, if you can't see, so this is a recorded –

Rick: Yeah, well Jessica's just sort of bent her little finger back, I mean, beyond 90 degrees, so yeah.

Jessica: [00:26:58] Yeah, it doesn't hurt, don't worry. You're flinching.

Rick: I am flinching.

Jessica: [00:27:02] It's okay, it would hurt you, it doesn't hurt me.

Rick: Yeah, I'm not going to try it.

Jessica: [00:27:05] No, that's alright. Yeah, I'm just very, very flexible, what that means is that I overflex a lot of the time and it's very difficult for me to hold my bones together, to be honest, they're very floppy, and I tend to dislocate things often. I dislocate the tips of my fingers constantly.

Rick: Really?

Jessica: [00:27:22] It's really annoying, like I'll pick something up, and because ... see it flex back so much? It's very loose.

Rick: Yeah, yeah, yeah.

Jessica: [00:27:29] So only this bit actually touches. Anyway, I'm making a pincer motion here, it's very difficult, and then the tips of my fingers dislocate, and then that really hurts, but yeah, so my joints hurt a lot of the time and then that's really exhausting and quite distracting because of the pain that you're going through. Then I also have brain damage from going through a hospital



procedure that went wrong when I was a teenager, which was in a quest to find out why I had paralysed my arms and what had gone wrong, and that means that I have a lot of difficulty with memories, [00:27:59] so I really struggle to make short-term memories and to hold them in my brain, and I often just have no idea what's going on, and if I don't write something down the second I have had that thought it will be gone forever because the memory was not made. So that's why I use my calendar app, to be able to just ... I put it as a whole day notification, but it's actually something like 'Buy dog food', I'm like 'Ah, thank you, phone, you're brilliant'.

Rick: That's what they're there for, they're handy.

Jessica: [00:28:29] Yeah, and then it rings twice a day to tell me to take specific medications which I need to take at specific times, and then, for communication when it comes to being deaf, my phone is absolutely vital and it's amazing, whether that's because I lip read a lot so I need to light people's faces, for instance, in a club or pub; in a club, I don't go clubbing, in a dark place!

Rick: Yesterday, yeah, you're fooling no one.

Jessica: [00:28:56] Oh my god. No, in a dark restaurant or wherever, so then it's easier for me to lip read, or there are a whole number of apps that are quite helpful. There's one called Big, where you just type stuff in and then it comes up and it's big.

Rick: It's a good name for the app.

Jessica: [00:29:14] Yeah, they thought that one through.

Rick: Very on the nose.

Jessica: [00:29:15] Yeah, yeah, which is great, because then you can show it to someone else who's sitting on the opposite side of the table without having to get some light and yell a lot, which is quite helpful.

Rick: Is there much in the way of apps specifically targeted for deaf people, to help deaf people?

Jessica: [00:29:33] It's kind of an interesting thing, because a lot of things that are created for deaf or disabled people that able bodied people use, they're like 'Oh yeah, this was for us, yeah?' No.



- Rick: Yeah, 'Hands off'.
- Jessica: [00:29:46] But when it comes to apps and stuff, if we're thinking about, say, for instance, Instagram stories, right, most people will look at their phone with the sound off, most of us have our phones on silent, we're scrolling through social media, we don't want videos to be making a noise, and that means that videos have to be captioned. So a number of apps that were created so that people could caption their Instagram stories or caption videos so that people who are deaf or hard of hearing would be able to use them and be able to understand, [00:30:17] but then it's also helpful to hearing people or people who have English as a foreign language or are watching someone in a different language, to be able to really kind of clue in to what's going on, if you're in a busy place, for instance.
- Rick: And do you use a specific subtitling app for your YouTube videos?
- Jessica: [00:30:35] No. See, the joy is, and this is why I love YouTube, is that YouTube has inbuilt caption facilities.
- Rick: It just does it.
- Jessica: [00:30:42] It has auto-captions, which aren't amazing, they're not the best, they're working on them, they're improving all the time, but you're able to go into those automated captions and you're able to edit them, which I actually really advise that people always do because that helps the machine learning, so the more you edit automated captions the more the machine is going to understand –
- Rick: It gets better.
- Jessica: [00:31:03] – your voice and understand how to phrase things correctly, but you can also then upload a separate captions file, you can caption it right there on YouTube, it's wonderful. Then we go to something like Instagram, let's just throw some shade their way for fun.
- Rick: Yeah, go on.
- Jessica: [00:31:22] Instagram Stories, why is there not an inbuilt captions feature?
- Rick: I don't know the answer to that, it feels like there should be.



Jessica: [00:31:29] Yeah, it does feel like there should be.

Rick: Also, and again, like you say, it's not just useful for people who are hard of hearing or deaf, it's useful for everyone.

Jessica: [00:31:39] Yeah, exactly, and we've got apps out there like Caption This or Cliptomatic or Clips, which is Apple's own thing, where you are just able to caption yourself, record yourself, captions come up at the bottom, you can edit those captions, then you have to save that from that separate app, then you have to take it over to Instagram Stories and put it up on your Instagram Story.

Rick: So can you use one of the other apps to get ... no, I suppose you can't, to get captions on to Instagram Stories?

Jessica: [00:32:08] Google Pixel apparently has a function where it will caption any media that's playing on your phone.

Rick: Oh, so that would do it.

Jessica: [00:32:15] Yes.

Rick: That's cool.

Jessica: [00:32:16] I want to get my hands on a Google Pixel, I think that's the newest one, the Google Pixel 4 or something, which I really want to try out because, if I had that, that would make quite a difference.

Rick: Yeah, that sounds great.

Jessica: [00:32:27] I know.

Rick: Where next for you, what's happening in 2020? I mean, I can just have a look in your calendar I suppose.

Jessica: [00:32:34] Well I'm going to Rome next week, that's very close in 2020, I'm going to go and celebrate the fifth anniversary of our engagement.

Rick: Congratulations.

Jessica: [00:32:44] Thanks, because we got engaged on my birthday. It was very romantic, my wife took me to Rome, we'd only been dating for four months,



and then on my birthday, at sunset, top of Il Vittoriano, looking out over the Coliseum, she was like 'I have your birthday present' and handed me this big book, and I was like 'Oh'. Then I took off the wrapping and it wasn't a book, it was a box in the shape of a book, and it had a little card that said 'Although this book has no pages, inside is the start of our story'.

Rick: Ooh, she's good, your wife, your wife's absolutely nailed that.

Jessica: [00:33:16] I know, and then we Facetimed my brother and his girlfriend and my brother was like 'Oh for god's sake, how can I top that one?'

Rick: I was going to say, that's a nightmare for him.

Jessica: [00:33:26] Yeah, poor kid.

Rick: When I have looked at your calendar it looks like it's just jammed.

Jessica: [00:33:33] Yes.

Rick: Absolutely jammed.

Jessica: [00:33:35] I'm a busy lady, what can I say? Yeah, no, lots of things happening, lots of things to do, yeah. I don't know though, YouTube is funny, it's a very weird world where you'd be like ... you completely jinx yourself, because you go 'Oh yeah, lots happening at the start of this month, nothing on for next month, looks very empty', and then someone gives you a call, like 'Hi, I need you to be somewhere in two weeks, it's the opposite side of the world, [00:34:03] you'll only be there for two days, enjoy the jetlag', and I'm like, 'Okay, okay, what an adventure'.

Rick: That's the thing, you've got to take these things in your stride I suppose.

Jessica: [00:34:11] Well exactly.

Rick: Do you socialise much with other YouTubers, do you know the YouTube community particularly?

Jessica: [00:34:19] A bit. I feel like I've come a bit late to the YouTube game, because most people in the kind of British YouTube community have been doing it for 10 years and I'm like 'Hi, I'm the new kid'.

Rick: 'I'm here now'.



- Jessica: [00:34:31] 'Don't [hate] me, can we be friends?' Yeah, so sometimes, sometimes. I really love events like Summer in the City, and we've got VidCon London coming up in February, really looking forward to that, because I grew up as a Quaker, which is a religion.
- Rick: Oh really?
- Jessica: [00:34:47] Yeah.
- Rick: Yeah, yeah.
- Jessica: [00:34:48] And we used to go to Quaker camp and like Quaker drama clubs, and we'd all go together with our friends for a week or a little weekend, and it was like summer camp, amazing. So I feel like YouTube conventions are like that, it's so great.
- Rick: So VidCon is like a sort of secular Quaker trip.
- Jessica: [00:35:04] Yes, it's wonderful. So the evenings you have a little party, and then you go to someone's room and just stay up chatting, it's great fun. I've actually made some of my now closest friends through YouTube, it's been wonderful.
- Rick: Okay, so you've got your phone out, I'm just going to ask you a few things. What's your most liked post on Instagram in 2019?
- Jessica: [00:35:24] Oh my god. Okay, let's find out. Oh, it's obviously a picture of my wedding anniversary, well it's a picture of my wedding.
- Rick: Yeah, the wedding.
- Jessica: [00:35:35] There you go, who doesn't love a picture of a wedding?
- Rick: That's good, that's a good cake as well.
- Jessica: [00:35:39] It's very cute.
- Rick: Yeah.
- Jessica: [00:35:39] Yeah, just my wife and I, laughing, happy.



- Rick: And last Twitter DM you received?
- Jessica: [00:35:49] Oh, I don't have open DMs, so this is going to be –
- Rick: Oh.
- Jessica: [00:35:55] Oh, it is from a girl called Gemma, who is absolutely lovely, and my very first Vlogmas video I went and surprised her, she's got all my subscribers, she's been a subscriber for a really long time, and her grandfather had just died and she posted on Twitter that she was quite upset. So I arranged with her girlfriend to surprise her with an afternoon tea in London and a hamper of goodies, including some Taylor Swift stuff that she really wanted.
- Rick: That's very cool, I like it.
- Jessica: [00:36:21] Yeah, so it's Gemma saying thank you and that she really liked the video.
- Rick: What was your last Google search, what was the last thing you typed into Google?
- Jessica: [00:36:28] Oh my gosh.
- Rick: Oh I'm excited.
- Jessica: [00:36:33] Oh, it's called Monti Kids, it's about Montessori –
- Rick: Oh okay.
- Jessica: [00:36:38] – because my wife and I are thinking of having a baby and we've become obsessed with Montessori education.
- Rick: And so you're going to go with Montessori if you have kids?
- Jessica: [00:36:47] Yeah, because I would have loved to send my children to Quaker school but there isn't a Quaker school in or around Brighton, so Montessori instead.
- Rick: Montessori it is. What time does your alarm go off in the morning?
- Jessica: [00:36:59] Ooh, it went off at 6.30am this morning. I tend to actually not wake up with an alarm though, I wake up at 7 on the dot every single day, it's



like a weird reverse insomnia, no matter what time I go to sleep I wake up at 7.

Rick: That's quite good though, isn't it.

Jessica: [00:37:16] It's quite handy, yeah.

Rick: I like that, yeah.

Jessica: [00:37:17] And then I go downstairs, make my wife's lunch, make her some tea, bring her some tea. she can't do anything without tea in the morning.

Rick: Is she British?

Jessica: [00:37:25] Well she's half British, yeah.

Rick: Yeah, that's enough, we do like tea, don't we.

Jessica: [00:37:28] Yeah.

Rick: Who is the most famous or most interesting person in your contacts?

Jessica: [00:37:34] That's probably Stevie Boebi, my friend, who is another YouTuber who makes lesbian sex education videos, and people think it's very strange that we're good friends because I'm like sweetness and light and she looks like some kind of grand wizard at all times.

Rick: Got you.

Jessica: [00:37:52] In black and purple velvet –

Rick: And did you meet through YouTube?

Jessica: [00:37:56] – with a cane. Yeah we did. Yeah, we met at VidCon out in LA.

Rick: At a sleepover?

Jessica: [00:38:03] Pretty much, yeah. She actually just got my wife drunk, I was asleep in bed and my really drunk wife came in and just threw herself on top of me, and was like 'I just met someone great', and I was like 'Cool, who?' 'I can't remember her name but you'll know who she is'. I was like 'Okay, any descriptions?'



Rick: 'She had a cane'.

Jessica: [00:38:21] Yeah, 'Purple hair', and I was like 'Well that just has to be Stevie Boebi then', that's how we made friends.

Rick: Just before I let you go, and I will let you go shortly, what's the single message that you would want people to take out of your YouTube journey, and actually your journey in general?

Jessica: [00:38:41] Wow, what a nice and simple question, thank you for that one.

Rick: Yeah, no problem.

Jessica: [00:38:45] Kindness, I imagine. I think that we all need to be kinder to each other, to ourselves, and to give everyone the benefit of the doubt.

Rick: That's a lovely way to end.

Jessica: [00:38:56] Thank you.

Rick: Jessica, thanks so much for talking to us.

Jessica: [00:38:58] Thank you so much for having me.

Rick: Have a lovely packed 2020, and enjoy VidCon.

Jessica: [00:39:02] I will.