Do you self identify as **disabled?** #00:00:42.1#

Um, not in as conscious a way as that. But in a way I have to, because the law suggests that I am. But, because I think... I haven't actually looked up the definition of disability but I think it is impairment for everyday activities I think so, if you have something which impairs your everyday life, so in that sense I am. Although it's quite an uncomfortable thing to... think **about** #00:01:26.3#

and so... so, #00:01:29.1#

I'm more comfortable with it now, so I suppose yes I do, but I rarely say it out loud, but I do sit in the disabled seats in the buses with no fear. And if anyone is going to challenge me, I would say **something** #00:01:45.7#

I haven't looked at any radical disability **stuff** - #00:05:58.2#

in this context I don't think we have to talk... I'd be happy for us to just talk about our experiences, we don't have to talk about theory – #00:07:24.2#

no I just want to show you where, my experience of first thinking 'am I **disabled?'** #00:07:31.1#

and having to justify it. #00:07:33.0#

Completely justify it. That is, yeah – **you can have a look at that -** #00:07:39.1#

Which is because you have to surely? #00:09:53.8#

I'm worried that if I want to start working a bit, if I feel well enough to, that I shouldn't as it may effect my benefit, as my illness is kind of invisible and it comes and goes, if I start working when I feel okay and then they think well she's well enough to work now, and I get sick again...again it's massive guilt on how do I fit in with **that.** #00:09:55.2#

Because the ESA doesn't support **you fully** #00:09:58.6#

Because there is... god, it's so complicated. the reason I know I'm not legally classified is because I tried to get a train pass [laughter] for disabled, but you have to be registered as disabled, so I'm not. But, so, maybe I'm not legally, but I am socially? and I am benefit-wise. But the, I think the distinction, you'd have to look it up or... but I think the distinction between... between being chronically ill, sick and disabled, there is a **distinction.** #00:02:33.7#

But I know I'm on the benefit which is for being chronically sick, but I don't know the changes because you don't have disability benefit anymore – it's changed. So I don't know if it's all been melted into **one?** #00:02:48.4#

so when did you first come around to thinking, oh shit I need support? **I need to** – #00:07:44.3#

Well, I was working at my job – #00:07:49.3#

What sort of job? #00:07:50.6#

It was working for [redacted] and I gradually... over two years, I started off full-time, and gradually not necessarily immediately to do with my illness but it worked out better for me – I think I was upfront about my illness, not actually to the [redacted], but to my immediate line manager and not when I worked the first job – that's another issue, I've never ever been upfront with employers about having depression or my illness. Until, I guess, I started working for myself. How are we **going to deal with this** – #00:08:41.1#

Sure, yeah of course. I am better than I was last year, but there is no saying that it won't go down again. But that's the nature of the disease #00:10:13.0#

And so, are you considered disabled **medically?** #00:02:56.2#

It's really ambiguous. I can get discounts for certain things, like medical supplies on certain websites by saying that I have a disability that I am medically disabled, I think people would use that terminology yes. Can we look it up? #00:03:25.2#

So basically my answer actually does make sense, because it's classified between

- #00:05:10.5#

I was thinking we would be anonymous **-** #00:08:45.0#

ok – #00:08:45.3#

or when it comes to - #00:08:47.2#

maybe let's not say [redacted]? Let's say, I don't know, I'm a cultural worker. To be **really anonymous** #00:09:07.9#

There are ways around it in how we **transcribe this.** #00:09:12.0#

You can say I work in the culture sector. It doesn't have to be me. #00:09:17.4#

That's something we can do when we transcribe and edit it. #00:09:21.5#

it comes down to how the government deals with you. #00:05:13.8#

Right, which is what our conversation is about – in a way your experience is framed by trying to gain access to support, governmental support, and that is actually what is defining the experience of disability **-** #00:05:28.5#

well totally, I don't sit around and think about... you think about [how] you can't do things and you don't... there's no reason actually to use that term apart from externally justifying – the government – you don't, you know... but then saying that,

I want to be, I want to be – there's the whole issue of an enormous amount of guilt around every single part of being sick. To do with everything. Everything it comes into contact with in your life and that is one of the major things. I am claiming **Employment and Support Allowance (ESA)** and I can't come off it because I would never get it again. But you're always made to feel that you don't deserve it, or you're cheating somehow. But I am trying to do a bit of work, up to how much I can do physically, if you know what **I mean?** #00:09:51.8#

Are you recording? So the thing was, my claim was with a decision maker. Which is so weird and 1984 faceless. So it was on this desk in Ireland... in a big pile, with the decision maker... So I said 'look, my disease has progressed because of this whole thing and my disease is linked to stress and this is directly effecting my illness and I want that to go down on record' and I was so mad at this point... I was more mad than upset. I was saying, you're actually penalising me. They were going to use half the money that I don't get as nominal income, so acknowledging that I don't get it and still penalising me **because of it.** #00:02:29.9#

of course. #00:10:45.7#



So because your illness isn't one that is immediately visible to other people, there's a process of you having to make it so. #00:12:10.4#

You can't see anything. I'll have pain, but it's invisible to the outside eye. But, say, I'm bad and I'm walking to the shops really really slowly, I wonder whether people think... I feel like I look like an old lady, creeping along the road, maybe limping a bit and I think, how are people looking at me? I think about this a lot. Sometimes I can't be very speedy. Do you just think I'm being an idiot, walking really slowly? If I look completely fine to you, are you just thinking 'get a move on love'? I'm really conscious of things like that. When my hands are bad, it's quite hard to deal with change, I'm fumbling a bit at the check-out, really aware of what this person is thinking about me... That I can't cope with counting, **or something.** #00:14:36.3#

We were talking about dancing –

Yeah – did I talk about it any other time? #00:07:27.3#

I feel like it was after we talked about pilates, where so much of it is about a symmetry and movements that are impossible for your body now.

You asked me, how do I –

– no we were talking about – #00:07:42.1#

– strength. #00:07:44.9#

Was there ever any suggestion of how they thought you'd be surviving financially in this period?

No. I was telling them I was borrowing money... but not at all. I was telling them I have no money, I have no money, what am I supposed to do. Because the whole claim accelerated as I talked to someone on **Christmas Eve and I think because it was** Christmas Eve someone took pity and put me through to someone, I found out then the office that was dealing with the claim... which I never had before and I started speaking directly with that office and it was shortly after that that it sorted itself out. But no... I looked into emergency, emergency loans, crisis loans, but it's not really – it's a loan. It's not money. I don't know how they thought I was **surviving.** #00:03:38.3#

Inversely are there times when your illness isn't visible so you maybe don't have to - #00:14:55.2#

– talk about it? #00:14:56.1#

Perform it in the same way?

It's not performing, it's necessity. I never think about it as performing. #00:15:04.7#



I mean, it depends what you're interested in. I probably could do, say something, if I knew what you wanted. If you had an overriding question. #00:05:12.1#

Well, I suppose it is how we have a sense of ourselves, who you are as a person in the world, how these identities are constituted relationally. We have to narrativise ourselves – your own illness for these assessments, forms .

The illness I have, no one knows much about it. I think it's classed as a 'rare disease'. and actually that's why it's even classed as 'probable'. I'm treated with the drugs for another disease because they don't really know anything about it, which is really frustrating. A lot of it is patient led, which is forming your own narrative. I have to tell them what has been happening. There's nothing solid.

But is there a way where we could talk about passing? And how we are read? When you're feeling well is there a sense that you can pass - #00:15:54.1#

I can pass at any point. If I'm that sick, no one is going to see me, as I'm at home.
If I'm out – you tell me, you've seen me on and off being ill and well. Have you noticed me, what do you notice when I'm ill?
Do you notice anything that I don't tell you? #00:16:19.9#

I guess a lot of the time, I just sort of because of my own experience relate things to trans...

Does that information end up circulating amongst others with similar illnesses – ? #00:10:30.2#

What information? How you're perceived by the medical – ? #00:10:36.7#

More like, finding your own combinations of drugs, treatments, ways to gain access – this is often the case with hormones – – hang on I've gotta take a pill.

I'll pause it. #00:22:27.6#

Yeah, I was asking in the past, was it part of your identity to - #00:07:50.9#

Yeah. Yes. I'm a small, strong woman and I am quite proud of the fact [that] I was strong, I am an active person so there's definitely a gap now. Partly between how I am, actually, because I am still strong, but how I can't do as much as I used to. #00:08:42.5#

In the past you said there was something proud about - #00:08:55.2#

yeah, I guess it's a macho thing. It's unexpected, you're smaller but way stronger than anyone would think you are. I used to take on big blokes in arm wrestles, flat down. But now I can't do that, I have to be careful in the things I do. #00:09:34.7#

as a physically strong woman. She had really big bicep muscles. She was really strong. In terms of my gender, oh man I don't know, if I had to identify as anything I guess it'd be a butch-femme. [laughter]

I can see that! #00:14:05.8#

But in that identity... I don't know what the outcome of my disease will be, or what will happen. That identity might, might have to, completely change. I don't know. Maybe I'll have to get more coarse in my language to compensate. #00:14:59.0#

So we were talking about dancing – you were saying how – #00:15:14.1# No. I think – no. Initially, it's taken years to come to this stage where it is one... And it is me... And it is my identity now... And I feel comfortable talking about it, and it's fine and I can be open and out. It's taken years and practice to do that. When I wake up, I assess how I've slept and how that'll impact my day, when I eat I am making food that I am conscious are the things I need to eat to reduce inflammation – every action that I do is now a thought of how my body needs to be. #00:32:50.2#

So it's difficult in certain social situations, because –

I'll try to explain to them 'sorry I can't do this because I've damaged my back', or 'it will damage my back', and 'I have to have a good sleep' and all of that... to function. But in a lot of situations you're not going to be able to explain that, so I'm always worried I'm being judged for being slack or lazy. #00:10:37.9#

Do you think it gets tied into being a woman as well? #00:10:42.1#

Um – yes. I think that's what I'm concerned about. Not visibly showing my willingness to get involved, so yeah, I don't have that identity as someone who is the strong, get involved, active person who does help out and is quite physical and I'm conscious of that stuff. I don't want to be judged as a princess. [laughter] #00:11:25.1# That's interesting, isn't it, because you wanna be – #00:11:32.2# Yeah, we were talking about expending energy. Thinking about energy, when someone has limited energy. I've always really liked dancing a lot, and it's a really particular way of expressing myself that you don't find in anything else. But the desire to dance, I can't really do it anymore.

And does that feed into the feeling of guilt about being ill? #00:18:15.2#

Yeah, it's exactly the same. It's part of it. You're the same person but to be... I am... I was... I was going to say I was fun – but you know, there's different ways. I haven't changed. But my ability to do stuff has changed. I can't be out late at night, I can't be out dancing.

I'm always nervous that I have to move through those people to get somewhere and if one of them grabbed me to start dancing, I inevitably have to disappoint them and myself by saying no, or moving away. You're careful with your body, protective with your body. I genuinely feel anxious, 'oh god, someone's going to grab me.' There is definitely part of a social expectation that makes me feel boring, because I can't do it. I wanna press the point that I used to very much enjoy dancing. It's not that I have never danced. I love it. #00:23:08.5#

Well for me –

because it's the opposite. You wanna
be judged –

it ties into how I hold myself
physically, how I think about dance,
wanting to – that somehow biologically
I'm determined to be masculine, manly,
and that's related to a strength, and an
inflexibility, not gracefulness. And these
attributes don't line up with how I self
identify at all. #00:12:11.7#

Often part of the logic of exercise, or dance, or even labour, is that we push on through pain, develop resistance, learn to – #00:24:24.4#

Yeah, but if you have damage, if your body is damaged, there are obviously times you'll never be able to manage it. #00:25:20.1#

Well that's exactly the same, I don't want to be judged on – I mean I'm quite a, I'm tomboyish – there's a desire to be not – unfeminine in that role. #00:12:40.2#

So asking for help becomes gendered. #00:12:46.7#

Yes, totally. Totally. Reverting back to those stereotypes. Old stereotypes. But women then, women in the war, were working, they were physical, hard labour. They were strong. My Gran was my first role model

I am my body. I don't think it's separate and I don't think it's beneficial for me to think of them as separate. It has to be holistic. Because a lot of it is mental processes and attitudes to what's happening to me. #00:31:09.0#

So it never feels easier to distance your self from your body? #00:31:13.2# This transcript is of a recorded conversation between Patrick Staff and a project collaborator, undertaken as part of <u>Scaffold See Scaffold</u>, THE SHOWROOM 2014. Recorded, transcribed and edited between June – July 2014.

<u>Scaffold see Scaffold</u> is a project by artist Patrick Staff exploring how bodies are presented, produced, represented and assessed within the fields of performance, healthcare, technology and labour; disability, queerness, austerity and flexibility.