

Patience podcast

Episode one transcription

Charlie speaking: Welcome to Patience, a podcast about living with chronic illness, I'm Charlie Fitz and I am sick of being patient.

[Music fades in, a reflective piece led by fluttering pianos and an electronic kick drum, music lasts for 30 seconds and fades out.]

Charlie speaking: I am a patient speaking from personal experience, I am not a medical professional, and nothing said on this show should be taken as medical advice.

So this is the first episode of a podcast that I am starting so it's gonna be a little be different to how the following episodes will be. First of all I am going to talk about who I am, why I am making a podcast, what is the patience podcast?

So who am I?

I'm a person in my mid to late twenties, I have fairly severe, complex chronic illness and disability. I identify as a cis woman, pronouns she/her/they. If I don't know someone else's preferred pronouns I will always try to refer to them as they or them. If I slip up feel free to comment and pick me up on it because I should not be slipping up on this.

I am white and, British and I have drifted in between working class and middle class throughout my life but I have had pretty steady access to a lot of the privileges of the white British, Southern middle classes. And why I am bringing that up or why is that even an issue? Well for the purpose of a show that discusses the inequalities faced by someone living with a severe chronic illness and disability and for me it is important to contextualise my experiences and recognise my privileges. Because even though I do fit into the category or I do self-identify as disabled I still have access to a lot of privilege within that category. I am diagnosed because my privilege, so I probably wouldn't have a diagnosis if I hadn't had access to some of the things I have had access to. Particularly because my illness is "rare" or more accurately as many specialists believe it's rarely diagnosed.

I have first-hand experience of some of the inequalities in healthcare faced by women, but I am interested in highlighting issues of inequality in healthcare in all areas whether that's through interviewing people on this podcast or signposting to other podcasts, vlogs or activists who are talking about healthcare inequalities due to Religion, race, background, being trans, being a sex worker and so on. I really think it's important not to speak for other people or to take up space that other people should have, so instead of just talking about these issues I will try and signpost or quote other people, instead of talking for them.

So why make a podcast?

Since becoming severely ill, roughly 4 years ago podcasts have been a lifeline for me. So whenever, depending on how ill I've been at the time, whenever I've been trying to get on with my day or trying to do something listening to podcasts has been a way of having another person's voice or helping me with the kind of social isolation that you get from being taken out of the workplace and taken out of your education and taken out of ... most of society. I started listening to podcasts of all kinds; pop culture podcasts, crime, fiction, economics, politics, comedy, food, and illness and disability is something I have only recently really started getting into because initially the podcast was a way of taking my mind off of my illness and disability but now I am pretty much fully diagnosed and I am

really ready to start, kind of, fighting for the illnesses that I have for disability, I'm more interested, I'm interested in connecting with other people and learning more about it. So why podcast? Their a great distraction from pain if your ill or in chronic pain and like I said really helpful with social isolation.

So why make a podcast about the experience of surviving with a chronic illness and disability in the UK?

I have hypermobile Ehlers-Danlos Syndrome or hypermobile EDS for short as well as many other comorbid illnesses, comorbid just means illnesses that are associated with each other and I won't get into right now. But Hypermobile EDS is a genetic connective tissue disorder and it's currently considered a rare illness although it's kind of on the cusp of not being rare with the amount of people who have been diagnosed and most of the people who are specialists whether you are a patient expert and you have just learnt a lot about it or whether you're a medical professionals who works in that area most people who know anything about it think that it's not actually a rare disease and that it's just rarely diagnosed. And it's a real spectrum so some people have it quite mildly whereas other people have it very severely and have lots of comorbid illnesses

Most medical professionals or most people who aren't experts in that area have never heard of it or if they have, or have a very strange misunderstanding of it. So, if you go to A&E most of the time you know far more about the illness that anyone there who can help you. It can affect almost any part of your body, it's a spectrum like I said so it can be really mild or really severe and it can, at the more severe end it can lead to quite severe disability and daily life-threatening complications. I'm kind of on the cusp of severe, you know there are people who are worse off me but I have many of the complications, I'm, you know, at the level of fairly disabled by it.

Once you get a diagnosis in the UK, if you get a diagnosis, unless you research, oversee and really fight for your own medical care you will most likely be left untreated, there are no clear pathways or treatment plans in place. There are a couple of hypermobility units in the UK or hospitals that have specialist clinics but they firstly, the waiting list to get onto them is ridiculous and secondly if you get into one of these clinics you often go, have an intensive course and then your left again. So there is no, kind of person, one person fighting for you, you really have to take on all of that yourself and that is actually the case for quite a few chronic illnesses. Especially ones that disproportionately affect women.

I've survived this far because of my privileges, I've had access to private healthcare in part, because I had access to university online databases and was able to research, because I was able to stop working and move in with family, so I was able to dedicate the time to research and really find really find the diagnosis myself, obviously I didn't diagnose myself but I sought out the people to diagnose me and also truthfully because of vlogs and podcasts and online activists I was able to make so many connections because of people with EDS who were out there making content. Which is why, I guess why I want to make a podcast and why I think this kind of thing is so important.

So though I don't doubt there are some great chronic illness and disability UK based podcasts and vlogs out there and I'm really up for any recommendations if you have them it does feel like there is a need for more UK voices to share their experiences in accessible ways, particularly in the EDS community but also in the wider chronic illness and disability community. And also I am really organically collecting a lot of really useful and empowering knowledge about the experience of disability and chronic illness in the UK, whether that's through talking to other people, my direct experience, you know trying to get help and trying to access things, through accessing benefits, etc and through my reading. So I feel like I'm getting all this information, hard fought for information and it might help, even just one other person to put it all in one place.

And yeah, so through making this podcasts I can share some of that information in a way that is sustainable for my own health, more sustainable than say writing to each individual who asks me questions online or in each facebook group or writing articles because with brain fog, which by the way will explain some of my abrupt stops and fatigue and all these other things going on it's hard to write all this stuff up so podcasting can be a more sustainable way for me to share some of that information. And also, as well as speaking of my own experiences and relaying the experiences of others and like I said signposting to activists maybe getting some other content creators on the podcast. But like anyone I cannot be expected to speak for an entire community and I would never try to do that all facets of identity are nuanced, and disability and chronic illness is nuanced and individual. So I am speaking from my own perspective and I welcome any criticism or different opinions and discussion.

So what is Patience Podcast?

Which I hope I have in part answered this from my rambling. [Canned laughter] But it's a podcast about living with chronic illness and disability in the UK. I have named the show ironically, as I have had some fairly bad encounters with some medical professionals and don't get me wrong, I love, I love the NHS, I have had some amazing doctors, some amazing nurses but I have also had some really really frankly, what's the word I am looking for, traumatizing, traumatizing experiences with medical professionals and I have had to be really active, like I said in my own healthcare. And most people with chronic illnesses really have to fight, so when I thought about the word patient and where it comes from the word patient and the word patience both have the same origin from the word, and I don't know if I am saying this right, 'Patien' which means to bear or suffer. And that just really irritated me, the idea that the patient is kind of silently suffering and they're not active at all in their healthcare, they are just at the whim of the doctor, it just irritated me. So I am sick of being patient, essentially, I'm sick of patience. So the title is ironic. The word for me symbolises the historically passive nature of the patient, who has no active role or power in their healthcare, something that I really kick against for reasons that can fill their own episode and probably will be a future episode.

The podcasts is part of a bigger project of artworks, articles and content I am creating, slowly but surely, under the title 'Sick of being Patient'. I do not have time to be submissive to a healthcare system that was built to fail me as a woman with a rarely diagnosed, complex list of chronic illnesses. I want to engage with many topics that interest me through the lens of illness and disability; so specific illnesses, history, healthcare, politics, injustice, inequality, art and pop culture. So you know, just the small things. My mind is a very messing place that jumps around topics, but I will plan and try to make the podcast as coherent as possible.

I aim to start by putting out an episode each month and seeing how that goes, in terms of my own health and how sustainable that is. Each episode I plan to start with a quick illness and disability news update, firstly one for the UK which I think is really important because I have found it harder to access that information, I've found it really easy to access information about America and quite difficult to access information about what's going on in disability and illness in the UK. So firstly that and then something of the wider world. And then the bulk of the episode will be on a topic, such as; What is Ehlers-Danlos Syndrome or discussing illness memoirs or some of the issues faced when having an invisible illness or disability etc, sometime I will be talking alone and sometimes I will be having a discussion with someone else. Either a friend or a family member or someone I have invited on, a content creator. And then I plan to end the show with something positive related to illness or disability because I think that will be good for mine and the listeners mental health.

And finally, with recommendations, either other podcasts, vlogs, tv shows, movies, bands some of my favourite podcasts do this they dish out really great recommendations. And I think it's good to uplift other voices that are important to you, other people and pay homage to your influences and things that have inspired you, which I am hoping the recommendations will do. And as this is the first episode I am doing things in a slightly different order introducing the podcast and myself has taken up some of the main kind of topic time and the rest is going to be about just setting the tone of the podcast.

And I guess the tone of the podcast is impatience and anger at the injustice and inequality faced by people in the UK with illnesses and disability, frustration at the lack of awareness of these injustices and anger at the disbelief when people learn about them, I guess that's not right not anger at the people who disbelieve it, but I suppose more anger at the blatant lies that we are told to try and cover up the injustice and human rights abuses. Because that's a continuous thing, especially in the UK we have this weird hangover that the UK is great because of the empire which we all know was not great and so that's a real kind of strange thing and I guess potentially they do it in America a bit as well, this idea that we are these leaders in the world when actually, we're just not, so yeah, so that's the tone.

So this episode is a very politics heavy episode and I will try and vary the intensity of episodes, but trigger warning, I do get angry a lot, I do get political a lot because for me everything is political and when I am in the company of people more content with this bullshit Government I do not know how to separate people from their politics, I don't think people get to be let off that easily and I think political; complacency is a privilege many people, including many disabled people don't have the luxury of because politics for many of us is life or death. So yeah, trigger warning, I get political and I get angry and if your not about that then, you probably won't enjoy it. (giggle)

So I get a lot of my chronic illness and disability information from social media, mostly twitter and other online Spoonies. A Spoonie, for those who don't know is a term many people with chronic illness use to refer to someone with a chronic illness, either themselves or someone else it refers to something called the spoon theory, a theory created by, now hopefully I will say her name right, Christine Miserandino who has Lupus, which you can read in full on their website butyoudontlooksick.com but in short, but to summarize or to try and capture their theory Christine used spoon to represents units of energy as they tried to explain the experience of rationing limited energy when you have a chronic illness to their friend.

So the basic idea is that a healthy person doesn't really have to think about how much energy a task will take, because, for the most part they feel like they have unlimited energy but when you have a chronic illness, and it's obviously different for each person. You may only start your day with 5 spoons and a spoon goes every time you do something, so you have a shower that's a spoon gone, you eat food, that's a spoon gone, you do something else, that's a spoon gone and when the spoons have run out you physically cannot do anything else. So it's really trying to break down the concept of rationing your energy and it does it really well. So Spoonie is a very widely used word and I will use it throughout the podcast, anyway I digress, I get off topic.

I also get a lot of my UK based disability and illnesses related news from a great website called Disability News Service, DNS for short, it's really good. You can follow the founder on twitter [@johnpringdns](https://twitter.com/johnpringdns). And I also get disability news from Disability Rights UK and other disability charities, sadly very rarely from any UK mainstream media, although Francis Ryan who has a guardian column and they put out some great disability content and you can follow them at [@DrFrancesRyan](https://twitter.com/DrFrancesRyan) on twitter. So that's a few of my trusted sources.

So let's set the tone.

For those of us who follow disability and illness related news, this isn't really news but it's a good way of settling the tone and it is incredibly, incredibly important and it really set the tone and it is incredibly incredibly important and as I say it really sets the tone in regards to the chronic illness and disability situation in the UK in regards to illness and disability at the minute and of this podcast.

So Theresa May (Booing crowd) who I will speak about a lot and who, not gonna lie, not one of my favourite people and her Conservative Government, again not one of my favourite things continues to claim that the UK is a leader in disability rights. A leader in disability rights! That's what they claim, continuously. However 'the Committee on the Rights of Persons with Disabilities' CRPD for short which was set up by the United Nations (UN) this committee which is made up of 18 disabled human rights experts. And as written on their website their goal, their global goal is to '...promote the rights and advancement of persons with disabilities within a broad mandate provided by the 'World Programme of Action' which was set out in 1982, 'Standard Rules' which was set out in 1994 and the 'Convention on the Rights of Persons with Disabilities' which was set out in 2006, I'm gonna say that again cause that's really important the 'Convention on the Rights of Persons with Disabilities' which was set out in 2006 as well as other relevant human rights and development instruments.'

So that's their goal. They're the people who can tell you if you're not doing enough for disabled people in your country and their experts. So one of their roles is essentially to monitor the human rights of disabled people in the member countries. And In September 2017 the committee concluded a review on the UK Government's progress, you know the leader in disability rights, concluded a review on the UK Government's progress or lack of progress in implementing UN's Convention on the Rights of Persons with Disabilities. That thing I just mentioned that was set out in 2016. So this is 11 years on. The Conservative Government been in for...

Oscar whispers: No 2006

Charlie speaking: Oh no 11 years on, how many years is that. It's 11 years.

Oscar whispers: Oh sorry.

Charlie speaking: You cannot count. That's my producer slash partner slash best friend slash carer Oscar just trying to tell me that my maths is wrong when its not it is right. But I am gonna ask him how long we have had a Conservative Government and I am also gonna ask him to include the ridiculous coalition with the Lib Dems which was basically a Conservative Government. Oscar how long have we had a Conservative Government?

Oscar whispers: 8 years.

Charlie speaking: 8 years.

Oscar whispers: Right?

Charlie speaking: I don't know if that's right.

Oscar whispers: 2011? 2010 election? Pretty sure, yeah.

Charlie speaking: Right okay 8 years. So a good chunk of that has been a Conservation ish Governments.

So John Pring who I spoke about earlier, who is the founder of the Disability New Service wrote a really good article about this assessment that they did, the UN did on the UK and their kind of disability rights and the article is called 'UK is going backwards on independent living, says UN committee'. Going backwards! The Government that continues to say they are a leader is going backwards and I'm telling you it wasn't very good in the first place. And I highly recommend going back and reading that on the Disability News Service website, you can click so it can play out loud to

you obviously if you're visually impaired but also if you're just exhausted and have a chronic illness and can't really read off the site it's really helpful.

So yeah, go back and read that if you can, but I am just gonna quote a few key lines from it here that are really brilliant and by brilliant I mean absolutely depressing. So here's the first one: "In its "concluding observations" on the progress the UK has made in implementing the UN Convention on the Rights of Persons with Disabilities (UNCRPD), the committee raised concerns and made recommendations on all but 3 of the 33 treaty articles it could have breached." (So all but 3, so that's 30 of them that it's basically not doing right.)

"It was, said the committee, the highest number of recommendations it has ever produced for a country undergoing the review process." (The highest number of recommendations, on this apparent disability leading country)

"The section highlighting the committee's "principal areas of concern and recommendations" was more than 6,500 words long, compared with a "positive aspects" section of less than 120 words which mostly related to actions carried out by the Welsh and Scottish Governments." So not so much to do with Theresa May's Tory Government.

A bit little lower down it says; "Stig Langvad, the CRPD member who led the UK examination, highlighted independent living as one of the areas the committee was most concerned about.

He said: "Persons with disabilities are in our view not able to choose where to live, with whom to live and how to live... [they]are still facing the risk of institutionalisation and not being able to live within the community." And this is something I can certainly relate to. I have an element of privilege, so I've been sort of okay. I've always had family that I can go and live with, I have a partner who cares for me and we do alright but in trying to access things we can really see how dire the situation is for us and for people who are worse off than us. It's completely inhuman, the situation. So every time, if you're in the UK or you're not in the UK, you hear Theresa May or anyone from her Government saying that the UK is a leader in disability, even in human rights because come on, we're humans, we are people, it's bullshit. They're not, they're human rights abusers. And they hide it at every turn and they lie at every turn. And you only need to look at this committee that is set up for exactly this reason and the results to see that their just liars. Anyway, it sucks, its not good, that's what this podcast is probably gonna be about a lot of the time, so.

You can read the full article at Disability News Service. So if we jump forward a year, that was in October 2017. Jump forward a year to September 2018 which is when I am recording this. John Pring, same guy has written another article on the Disability News Service about the Government's response or again lack of a meaningful response to the UN Committee on the Rights of Persons with Disabilities report of the UK's failure to implement the 'Convention on the Rights of Persons with Disabilities'. That article is called 'Government's response to 'human catastrophe' UN report is 'deeply unsatisfying' and again I strongly recommend reading it for yourself, if you have the time or listening to it.

The Government is given until 2023 to officially respond and I suppose the official responses needs to show all the things their doing, so that's why they give them such a long time, all the things they have put in place to respond to this report because it's a really huge report. But their kind of initial response to say that they are addressing it is basically to do what this Government always does and act like the report is wrong. So a Department of Work and Pensions (DWP) representative made an initial statement and the statement is beyond ridiculous. It basically mimics the reaction of anyone in a position of power or privilege who refuses to acknowledge that power and privilege and refuses to believe someone else telling them about their lived experience and about the kind of injustices that they are living under. [Sound bite of Ed Miliband being interviewed by Russell Brand Ed is saying "It's

just wrong, it's just like wrong... it's just not true." So a committee of disability rights experts, who are also disabled people are telling you, you are failing to meet most of the human rights for disabled people and their response is basically well we are sorry that you haven't recognise that we are actually world leaders in this area. This is literally the world appointed committee on disability rights, just listen to them. When a woman tells you she experienced sexism listen, when a person of colour tells you their experience of racism listen, when a disabled person tells you about their experience of ableism listen and so on and so on and so on and so on. But the Government doesn't do that.

So the Government spokesperson said: "We're disappointed that this report does not accurately reflect the evidence we gave to the UN, and fails to recognise all the progress we've made to empower disabled people in all aspects of their lives." Then they claim to be doing a lot for disabled people with various figures and conclude with "We're also a recognised world leader ["world leader" echoes] in disability rights and equality, which is why we supported the development of the UN convention." So you're being told your not a world leader by the experts you put in place, your not a world leader but they are and their sorry that this thing they put in place is ignoring that. This is a tactic that this current Government use a lot. They just lie.

You only have to watch Prime Minister's questions, which if your not from the UK or if your not quite as politically obsessive as I am you might not know about it. But on a Wednesday the Prime Minister allows people from the whole of parliament to ask her questions and it's televised and people often tune in for the bit when the leader of the Labour party Jeremy Corbyn questions her because that's meant to be like the big face off and she just lies. Whenever you watch it, Theresa May is asked a critical question and she lies, she says all the things she is apparently doing, which is normally false and then claims to be a world leader in whatever topic they are discussing at that time. So Theresa May your not doing enough for disabled people well actually we are doing this, this and this and we're world leaders in this, every single time. And this speaks to the jingoistic hangovers of the British Empire and all is forgiven in a strange bombastic nationalist patriotism weird kind of thing that is embedded into all Brits from school age onwards about Britain being the the world leader and the British Empire, it's just bizarre and it works no matter the actual evidence and Britain's actual record on all of these things, which is normally completely opposite to what they are claiming. I guess that's how nationalism works most of the time. Blindly loving a country because you happened to pop out of a uterus there but that is a discussion for another episode.

[A comedic and jovial accordion tune plays throughout the following speech]

So someone is standing on your shoe. You say "excuse me sir your standing on my shoe", Person looks down to see they are standing on my shoe, looks you in the eyes and shouts, "that's impossible you see I am the world leader of not standing on other people's shoes." And That is basically how Theresa May's Government currently responds to any criticism. World leader, world leader, world leader [echoes]. [Accordion tune fades out].

So now I've set the tone and if you are horrified and bored and scared then run in the other direction and if you have actually learnt something then I've hooked you. And now I'm gonna cover a quick bit of news, something good and a recommendation after that.

So UK disability news, still talking about Theresa May, apologies I will try and not talk about her that much in every other episode, she does not deserve this much time.

Theresa May has warned UK citizens to prepare for a no deal Brexit. Which is basically bad news for anyone who cares about the economy or human rights. And like anything will disproportionately affect the sick and disabled people. Disability Rights UK published a paper called 'The implications of Brexit for disability rights, Influencing future debate and policy by Anna Lawson and Liz Sayce' which can be read on the Disability Rights UK website. And if a no deal happens I will do an episode focusing on some of the damaging effects Brexit may have on people with chronic illnesses and/or disabilities. Some of the really big and likely problems are NHS staffing shortages, medicine and medical equipment that comes from or through Europe, a lot of employment rights and human rights in the UK is currently based on EU law so there is a very real possibility that current human rights standards which aren't really good enough for the sick or disabled in the UK anyway will be open to being undermined further. And probably will be by the people Theresa May's government are really serving, big businesses. Big businesses that don't keep their money in this country, just to be clear. And another big one activists are talking about is that the Government will be so clogged up, they'll be so much to do so many new laws to legislate for. That things that disability and chronic illness and any activists are pushing for will be pushed back because the Government will be busy trying to repair itself from the severe damage, from cutting itself off from... I don't know, I don't know, I'm done, Brexit, ridiculous. So yeah, that's the news.

And then my something positive which I'm gonna end on is a new hashtag, #NightinGales. Started by Jen Brea or Jennifer Brea. Who is a filmmaker, ME and chronic illness activist, she is American I believe, she is one of the founders of ME Action which is an ME charity, she made the film *Unrest* which I can not recommend more highly. I mean you need to really be ready, you need to be emotionally ready to watch it but whether you're ill or whether you're not it is a really really incredible film, you need to watch it. And you can follow her @JenBrea on twitter. And the #NightinGales is specifically to connect people with a variety of chronic illnesses; EDS, Hypermobility Ehlers-Danlos Syndrome, ME, POTS, Mast Cell Activation Syndrome, Fibromyalgia... and it's just to kind of connect these communities. Firstly because there is a lot of evidence to suggest that they are actually scientifically connected and secondly they share a lot culturally, they share a lot of the same stigmas, the same problems in diagnosis, a lot of the same strange ideas that people have about them. So far it's just been a really beautiful hashtag to be involved in, connecting these people and hopefully something really cool will come from it. So I recommend checking that out.

One of the other really cool things about NightGales is that Jen Brea as far as I can see is very ill, which is obviously very sad and I'm also very ill and I find her really inspiring. And I found her film really inspiring so the fact that I have been able to interact with her has been a bit of a fangirl moment for me, which is quite cool. And hopefully if this podcast does anything good maybe we will interview her in the future. Maybe when this podcast has some solid listener base, so yeah that brings us to the end.

Oscar speaking: You can now pick that up from B&Q which is a home depot-esque store.

Charlie: What are you doing?

Oscar: Solid listener base.

Charlie laughing: Shut up. [continues to laugh]

Thanks for listening to Patience Podcast I produce and edit the podcast with Oscar Vinter my wonderful partner who composed the intro and outro music. You can follow him on instagram at...

Oscar: @OscarVinter

Charlie: @OscarVinter and on twitter at...

Oscar: @VinterPoet

Charlie: @Vinter Poet and his website is not finished yet, but when it is...

Oscar: It's been under construction for a while.

Charlie: I've been constructing it. And you can follow me on twitter @CharlieJLFitz and on instagram @CharlieJLFitz. And the website that you are probably listening to this on is sickofbeingpatient.com

Thanks for listening, see you next time, bub bye. Oh by the way this bub bye is how my 3 year old niece says bye, so that is probably something that I will always do.

[Music fades in, a reflective piece led fluttering pianos and an electronic kick drum, music lasts for 30 seconds and fades out.]

END OF AUDIO