

Charlie: Welcome to Patience, a podcast about living with chronic illness and disability in the UK. 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: 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.

If you would like to know a little about who I am or why I am making this podcast or the tone of the podcast please go back and listen to the first episode. This is the second episode of patience podcast and it's coming out a few weeks later than I had hoped it would, as I have had a very very very bad health month. But I'm making it and that's the most important thing. And hopefully I will sound a bit more chipper and less croaky than the first one because I listened back and you could hear how ill I was and I know that people like to listen to nice chipper voices. So I am having a go at that.

Joining me on the episode today is my partner Oscar Vinter.

Oscar: Hello, hello, hello.

Charlie: He is currently eating a pizza so he might not chime in for the first 10 minutes, I mean he might. He is eating a delicious smelling pizza.

Oscar: It's not gluten free, it should really be gluten free. But hey ho.

Charlie: Yeah he's meant to be eating gluten free, I can't eat any pizza so well jell. So I wanted to introduce him and talk a bit about our dynamic as a couple and our relationship to illness and disability. He is... we have been together for four years, as well as being my partner, my best friend, the bane of my life, my teacher all of the above.

Oscar: Not Bane as in, non-Batman bane.

Charlie: And he is also my carer, and he is a composer (a very good one at that) he composes under two artist names Vinter and Delphine & Xavier. (watch this space) and he is a multimedia artist, he does a lot of work with photography, film and music and he is currently in the process of applying for a Phd which has a focus on audiovisual composition I guess. So he is an individual of many talents. His pronouns are he, his, they. As well as being my carer and having that relationship to disability, he has also worked as a 1:1 teaching assistant with students with Autism. A job I also did for many years before becoming too sick to go out to work. He also has ADD (Attention deficit disorder), dyspraxia, dyslexia, social anxiety and suspects he has Autism. I'm dyslexic as well and I am a wheelchair user, but up until, in a few weeks time Oscar has always been the person who

pushes my wheelchair, so we have an equal understanding of the ins and outs of accessibility in relation to wheelchairs, cause my joints are too unstable for me to self propel. We are getting an electric add on which we fundraised for and my family helped with that and that should be here soon. So soon I'm gonna be back in control of the wheels. So we're a couple who are proud of the things that make us who we are and I guess we have an interesting perspective on disability because we both have invisible disabilities, my disabilities can become visible through mobility aids and braces and things like this. Where as Oscar has to choose to let you in on it. I mean, I guess there are some people who might be able to figure it out, but he has to choose to let you in on his disability. Would you say that's right? He's nodding, he's got pizza in his mouth but he is nodding.

So the episode today is gonna focus on a story about Assessment Treatment Units, which we will get to later. And basically whether we can trust the UK government to make the changes to them that need to happen. But first I am gonna do a little news piece.

UK disability news

So from the 1st November, which I guess is a little while back now but when I made these notes it was fresh news Medical Cannabis became legal in the UK however it's only legal for some medical conditions. It can only be prescribed by specific doctors for and after they have ruled out all other treatments options and after they have done a strict assessment of whether it is safe, I guess. The conditions included are multiple sclerosis; epilepsy; and nausea and vomiting caused by chemotherapy. And the change came about after the campaigning of the parents of two children with epilepsy, young boys and I think they were going abroad to get medical cannabis and it was the only thing stopping these kids having seizures.

Obviously it's still pretty strict laws. I mean you can get it for pain, for fibromyalgia, for Ehlers-Danlos Syndrome, loads of conditions that we know it has really good benefits for and the things that are being used instead are really harsh pain killers and things that can actually cause more problems than medical cannabis. So hopefully it's a step in the right direction.

Interesting, according to the UN the UK is the world's largest exporter of legal cannabis for medical use. We are the largest exporter, so we have tonnes of cannabis in this country just no one's allowed to have it. And the company that is exporting the most company British Sugar, they own the largest Marijuana producing greenhouse in the UK.

Oscar: Do they sell sugar as well or is that just a euphemism?

Charlie: I think so, we will have to look into it but I... British Sugar, I mean, it sounds a bit colonial right? We will have to look into the history of it. I wanna do an episode totally on medical marijuana...

Oscar: Or it sounds like cockney rhyming slang.

Charlie: You don't think it sounds a bit colonial?

Oscar: It could be all those things.

Charlie: Anyway that might be incorrect so don't quote me on that. But I want to do a full episode on medical marijuana. So we can look into that and look into the ideological reason as to why it's illegal blah blah blah. And the benefits to certain people.

So British Sugar which owns the largest marijuana producing company in the UK. The managing director of that company is a guy called Paul Kenward. So he essentially makes a lot of money out of having the monopoly on medical marijuana in the UK. And the looser the laws become presumably the looser the laws would become on producing and he would lose his monopoly and lose all the money he makes from exporting it. And obviously you can sell things far higher and get more money if you have to export them I assume than if they are made in the same country. Right? Well if it's illegal to have medical marijuana in the UK and you are making loads of it and sending it abroad I am assuming you can sell it for higher prices can you not? Than if you were selling it in the UK?

Oscar: Not quite sure.

Charlie: We're not quite sure, well anyway I will look it to that as well. By having really strict laws on it and by having a monopoly on producing it of course you're gonna make more money. So if more people can produce it in this country, there will be more competition in the market and prices will be driven down, that's just like basic economics.

Oscar: You know it's just the free market, it's what all these people say they want.

Charlie: It's what all these Tories say they want, when actually...

Oscar: Competition.

Charlie: So this guy, Paul Kenward makes a lot of money from having a monopoly on selling medical marijuana. And he just so happens to be married to Victoria Atkins, who is a

conservative MP and her position in 'Parliamentary Under Secretary of State for Crime, Safeguarding and Vulnerability', and a lot of people refer to her as the drugs secretary (correction 'minister'), because that role is the main role for drug policing and drug laws.

So she has had this role since November 2017, so her husband owns the largest Marijuana producing company in the UK and she has been the drugs MP since November 2017, it wasn't until the cannabis medical debate started heating up in May 2018 that she recused herself from conversations and the only reason she recused herself from conversations from this point was because people were picking up on the massive conflict of interest. She is directly benefiting from keeping it illegal and having harsh laws on it.

It's just another example of Tory hypocrisy. Yes?

Oscar: And it's also, this happens more frequently than people know about. Just like Theresa May's husband I am pretty sure he's on the board of G4S.

Charlie: Oh yeah, can you be heard from over there?

Oscar: I think so, I'm good, I'm good homes.

Charlie: Carry on.

Oscar: And Obviously the government has increasingly been offering G4S more and more contracts.

Charlie: Like the Olympics.

Oscar: Yeah stuff like that.

Charlie: And that was horrific, they offered G4S, it's a security company the Olympics deal.

Oscar: They failed their remit and had to bring in the army.

Charlie: Yeah, they totally screwed up.

Oscar: And cost the taxpayer a lot of money. But anyway it's a recurring thing that happens. It's definitely a grey area and it's not reported on as much because... I don't know. The rules surrounding it are very grey. But it shouldn't be a thing.

Charlie: You shouldn't be able to have a business, a massive, multi-million if not more business -

Oscar: And it so happens that your spouse, partner, husband, wife has direct controls and powers in relation to offering contracts or the decriminalisation of certain laws which pertain to your business.

Charlie: Yeah. I mean I guess that's probably how it's always been, if you think of who was allowed to vote, who was allowed to be in government from the beginning it was people who had land, people who had money so that conflict of interest was probably ingrained into how government was even set up I imagine. You know, we are the people who own these things, we wanna have our say and at that point I guess it was maybe expected but now they try to hide that fact. They try and say 'we're here for the people, we are voted in for the people, we're not just making legislation that will best line our pockets.' But, so so so many MPs, even, not just Tory MPs either, I know I love to be all down on the Tories but you know Labour MPs do it too.

Oscar: If you have a job as a member of parliament you shouldn't have a second job. You shouldn't have an advisory position on a... investment bank.

Charlie: All of them are landlords.

Oscar: Get paid forty thousand pounds for doing 2 weeks work a year. That's a conflict of interest. They get paid, what sixty thousand pounds a year.

Charlie: It should be enough.

Oscar: And their salary was recently up for review for increasing it. It's ridiculous. The average salary depending on (coughing, sorry, 'excuse me', pizza) the metric you follow is between twenty-one thousand and twenty-six thousand a year. That's the average.

Charlie: And their earning triple that in just their jobs as MPs. And their all landlords as well and they you know have so many conflicts of interest. But anyway this one I just thought this was really interesting because it couldn't be any more like obvious.

Oscar: And the fact that she has to recuse herself.

Charlie: And the fact that it took, when she was given that job, obviously there are other parts of it but a massive part of it is drug laws she should of said, well no sorry I have a

massive conflict of interest can I have another role. It's a joke, the fact that she only recused herself once people were getting a hold of it and being like 'hang on a minute'. (Coughs) Sorry this is what happens when I try to speak in a chirpy voice, my body tries to rebel.

I have a quote here from an article in the independent about this exact thing:

'Peter Reynolds, who the president of Clear, which campaigns for cannabis law reform said this was not just a case of a conflict of interest, but "hypocrisy on a grand scale."

He told the BBC: "The reason she was appointed referring to Victoria Atkins is that Theresa May was looking for someone who was a hard-line prohibitionist. The Tory party's policy on drugs - cannabis in particular - is directly opposed to the evidence, and Victoria Atkins is someone who supports that.'

<https://www.independent.co.uk/news/uk/politics/drugs-minister-victoria-atkins-hypocrisy-cannabis-paul-kenward-british-sugar-a8356056.html>

So she's a hardline prohibitionist as well, it's not like - I read one article, I think it was in vice.

Oscar: Boo

Charlie: That kind of, was trying to say did she recuse herself because she is secretly for legalising cannabis, because her husband has... it was just like really naively assuming -

Oscar: Vice is trash.

Charlie: Because her husband has a connection to it that, that was why she recused herself. She's a hardline prohibitionist because it makes her money, so she recused herself because it was getting to the point where it was becoming something in the media and she was being called out.

Anyway, so that is all I have to say on that for now and I think that we should do a full episode on Cannabis related to health and related to laws and the ideology behind it cause I think it's really interesting and we could go quite in depth on that.

There was one thing, did you ever find out where that quote was from?

Oscar: What quote?

Charlie: The 'ideology is precisely that which allows for contradictions.'

Oscar: It's from an essay on postcolonial literature, but that's besides the point. I think it's applicable to lots of things. So in the sense that, it kind of, you can view ideology as not merely a set of beliefs but the kind of, almost like the glue in between the contradictions in your beliefs and actions.

Charlie: So, why I bring this up, is that the Tories, a lot of the Tories and a lot of the Conservative party have very Victorian morals except when it comes to making them money. So they hold up these really intense Victorian morals for the things they want to do in Parliament etc but then if you dig into it.

Oscar: By the way Victorian morals aren't a good thing.

Charlie: Oh yeah. Just so everyone knows Victorian morals aren't a good thing in our opinions and anyone who values -

Oscar: Human rights.

Charlie: Human rights (both laugh)

Oscar: Just life it's self.

Charlie: So the Conservatives have pretty hardcore Victorian morals until it comes to lining their own pockets and then they will go against those. And that is what I have to say on that.

Topic.

Charlie: I am going to give a trigger warning before I get into the topic, as we are going to be talking about Assessment treatment units or ATU's and there will be mentions, not descriptions of but mentions of the abuse that is known to go on in those units. If that could be triggering for you or if you have lived through an Assessment Treatment Unit you may want to skip the topic today and go for to [1 hour 1 minute] for our something positive and recommendations sections.

So today's topic started as a segment for our new sections but I realised it really had to be its own topic as it's an extremely important often overlooked issue in the UK for people with disabilities and for anyone who cares about human rights. Which if you don't care about human rights then you either keep listening and learn to care or leave this space cause you are not welcome.

The news story that started this discussion for Oscar and I was a piece by John Pring over at the Disability News Service called 'Hancock announces 'seclusion and segregation' review... after 70 years of concerns'.

The article is about the reaction of Matt Hancock who is the Secretary of State for Health and Social Care in the UK. And the joke is I had to check if he was still in this position just before recording as Theresa May's cabinet is like a game of musical chairs, someone is resigning every 2 seconds over the Brexit deal or lack there of deal. How many people have resigned Osc?

Oscar: Since January at least 14 people. Not just from the cabinet per say but ministers as well.

Charlie: So I just wanna explain a little bit about the situation and essentially what we are gonna talk about, so the article is about Matt hancock, his reaction and the fact that he is asking for the situation to be reviewed. So we are gonna look into him a bit and decided whether we can trust him or the government to do anything about the situation. First of all...

Oscar: Firstly for those who do not know what are ATU's? They are Assessment Treatment Units. Is that right?

Charlie: Yeah, so they are essentially inpatient units or hospitals where people with learning difficulties are meant to go for short inpatient stays for assessment and treatment when they are in a moment of crisis. So why might someone be sent to an ATU? The charity, 'The Challenging Behaviour Foundation', which is a charity who states that their vision is: 'for all people with severe learning disabilities who display challenging behaviour to have the same life opportunities as everyone else and, with the right support, to live full and active lives in their community'.

I think the reason that its called that, is because, when I was training to work with children with Autism and I went to do training at specific centres and schools, one of the common trainings is called 'Managing Challenging Behaviour' and I think it's meant to be like a PC (politically correct) terminology for when people with learning disabilities might become

aggressive to themselves or others. I think 'challenging behaviour', I guess it kind of is a PC way of saying it. But obviously there needs to be no assessment of like good or bad within that because often these "challenging behaviours" in air quotes is as a result of misunderstanding someone's needs. So I know that there will have been, with some of the people I have worked with there will have been a whole host of things that will have happened throughout the day to cause a complete meltdown and at that moment in time, it will seem like the meltdown came from nothing. But if you really knew the student and knew the students triggers you could go back throughout the day and figure out all the little things that caused it. So I guess 'Managing Challenging Behaviour' was normally about recognising the triggers and better understanding the things that are really overwhelming for that individual. So I guess maybe it shouldn't be focused on the 'challenging behaviour' and it should be focused on people learning what that behavior is as a result of and reframing it in that way. But anyway I think it's a good charity, the idea is that it's to give people a better... to allow people to thrive in their communities and at home. Which is essentially what I would want. Wouldn't you? What do you think?

Oscar: Yeah I agree.

Charlie: You agree. So in a PDF that they have for people who may have had family members sent to one of these ATU's they give 4 example of why people might be sent to one of them:

Oscar:

- 1.They pose a serious risk to themselves or another person such as life-threatening self injury;
- 2.They have a mental health problem that has flared up and become serious and they have been detained;
- 3.They have committed a criminal act and their admission has been ordered by a Court;
- 4.There aren't the community-based assessment and treatment services available to them in their area.

Charlie: So the 4th one if the most concerning. There aren't the community-based assessment and treatment services available to them in their area. That is probably, I have nothing to back this up, except for my knowledge of what is going on in the country at the minute. That, I guarantee a lot of people are being sent to ATU's just because there aren't the services. Which is as a direct result of austerity. Austerity has hit local services the hardest. Local services are the things that will help people to live to their fullest in their community. And their being cut the highest so that... There are actually a few articles and assessments that have been done on this , that say the massive impact that austerity is

having on people with learning difficulties and disabilities and I will link some of those onto the episode page.

<https://www.independent.co.uk/news/health/learning-disability-nurse-training-bursary-nhs-cuts-tory-austerity-a8491681.html>

I have um, just to give a little bit of... what's the word... background. I currently have quite bad craniocervical instability which I will do another episode on, another day but it's giving me loads of cognitive issues so if I'm forgetting words or muddling words that's why.

Okay so I wanted to read a little bit of this article from John Pring so we can explain what this is all about. I am gonna read the first 3 paragraphs.

'Health and social care secretary Matt Hancock announced this week that he had asked the care regulator to launch an immediate review into "the inappropriate use of prolonged seclusion and segregation" and said that some disabled people had been "treated like criminals".

His call came following a series of media investigations into conditions in privately-run assessment and treatment units (ATU), facilities that are supposed to be used for short-term care if someone with autism or learning difficulties is in crisis and community-based services cannot cope.

The media reports have included allegations of widespread abuse, cruelty, physical restraint, poorly-trained staff and wrongful use of medication, as well as the frequent use of lengthy periods of solitary confinement.'

<https://www.disabilitynewsservice.com/hancock-announces-seclusion-and-segregation-review-after-70-years-of-concerns/>

Okay the first thing I want to look at in that, well firstly, it seems like he's. Well if you read that with no knowledge of the history of these things, you would be like, well okay, this guy seems like he's gonna do something about these things. He's called for a review. I know that he has written to the head of CQC to -

Oscar: What's CQC?

Charlie: CQC is the Care Quality Commission, and they... I mean, it does what it says on the tin. They are meant to... do CQC have anything to do with hospitals? I know that they have

stuff to do with care homes, cause my mum was a carer for years. And CQC are meant to keep the standards up basically. There have been lots of... I have read a lot of stuff that has mixed opinions about them, but I remember my mum saying oh CQC came in today blah blah blah.

Oscar: So they are like the ofsted of care homes?

Charlie: Yeah, they are like the ofsted of care facilities. I don't know if they have anything to do with hospital. I will get back to you on that. (Correction: The CQC are the care quality commission for all health and care in England, including, care homes, hospitals, GP services and dental services.) I don't think so, Care Quality Commission, you would think?

Oscar: Anyway that is a ...

Charlie: An aside.

Oscar: Well it's definitely an aside, but it's for another day. Because we think that, care in the community and all these things, such as care homes should be brought under national.

Charlie: Yeah of course.

Oscar: Like the NHS and be this cohesive.

Charlie: Because what's happening is when people like Matt Hancock are being pushed on the funding, they are like 'oh we're putting loads of money into the NHS and this, that and the other', their just changing how they talk about where the money goes a lot of the time. If you see accurate reports you will see that local councils are having their money stripped massively. I can link some more things about that, cause I read one really really intense report that said that local governments we're having their budgets cut by like 90-something percent. So I will find that and I will link that in too.

<https://www.independent.co.uk/news/uk/home-news/england-council-budget-cuts-government-austerity-social-services-essential-care-safety-a8559486.html>

Oscar: And the interesting thing is, well not interesting scary in this context is that local councils in England can't run a deficit. So whereas the NHS, or NHS trusts can run deficits and the government itself can run deficits.

Charlie: I didn't know that.

Oscar: A local council, they are given money and that is literally it. If they go above that, I can't remember what the process is, but it's not good.

Charlie: You need some water babe.

Oscar: No no

Charlie: Yeah you do, your mouth is going [makes moist lip smacking sound]

Oscar: Yeah cause there is too much saliva. Too much saliva.

Charlie: Um, I assume that everyone knows what running a deficit is, but if you don't it basically means that they can't go into debt. Like all, most governments they always have a deficit, they are always in debt, it's how governments run and your never expected to get rid of the country's debt because...

Oscar: Well that's what George Osborne wanted to do.

Charlie: Yeah but that's just ideology, that's him using that to back up his ideology. All governments, all countries run in debt that's just how the world works and it's fine, it gets paid back slowly. But anyway apparently which I didn't know local councils can't run deficits, so if they don't have the money for something, they don't have the money for it, which explains a lot. [30:44] [...] sorry I needed a drink. So going back to the language of that little piece which I just read. I really like to pick apart the language of MPs because I think it's so telling and Matt Hancock in that first paragraph I read he said that "Disabled people have been treated like criminals". Okay, we know that in these care homes people are being put into seclusion for months and months and months, if not years. We know that they are being abused and there's been loads of homes that have been shut down because of it. So this one particular case that Matt Hancock actually mentions in a letter to the CQC bossman is about an investigative piece of journalism by a journalist called Lucy Adams and she did a piece called "Transforming care, is it working?" its available on BBC file on 4 and it's an 36 minute audio piece of documentary and one of the people she looks at is called young woman called Bethany who is seventeen who has been in an ATU for years and has been in seclusion for months and one of the things that they mention in this, you should go and watch it, I'm gunna link it in is that she stabs herself in the arm with a biro pen and doesn't get medical care for days, so a biro pen is stuck in her arm for days. So if we just go back Matt Hancock says that "disabled people are being treated like criminals", which is true because we know that the state of prisons in the UK and in America is horrific. We know that the state of prisons in the UK is one of the worst it's ever been and we know

that they are being abused, left in horrific conditions, probably not getting medical care like this young woman who wasn't getting medical care. But to say that they are being treated like criminals you would assume that Matt Hancock thinks that that's appropriate treatment for criminals. Now I don't know about the people listening to this, I hope I've drawn the kind of crowd that thinks that criminals should be left in seclusion, abused and left without adequate medical care. I hope that I've drawn the crowd that think that there needs to be less prisons and less confinement and more...

Oscar: preaching to the choir eh...

Charlie: [laughs] more, what is it called? Rehabilitation. Obviously there are a really minute section of criminals who possibly can't be in society, however as someone who has been in bed and is often confined to a house or to a room through illness, I believe that taking someone out of society is, obviously if there's someone who really can't reform or be safe in the community, taking them out of society should be enough. Because it keeps everyone safe. I'm thinking about all the people who might be harmed rather than kind of witch hunt for punishment. Obviously if there's a family who have had something horrific happened to one of their family members and they want justice, then, who am I to say that they don't deserve some kind of punishment, but is not taking someone out of society punishment enough? Do we have to treat them as if they are not human beings and not give them human rights? I think no. What do you think Oscar?

Oscar: Yeah, ermm. I'm in agreement of course and I think our old friend ideology returns again. It's that, someone's done something bad so we're gonna abuse them, which is something bad in itself.

Charlie: [Cross talk] hypocrisy...hypocrisy...hypocrisy

Oscar: But they 'deserve' it because they bad and so we're gonna do bad stuff to bad people.

Charlie: But how did someone get that way? Like... I don't know. There's so many different arguments. Ideally, ideally though, I would wanna be like "get rid of every kind of confinement what so ever."

Oscar: Look at the Norwegian model

Charlie: Yeah they have a tiny amount of people actually in prison

Oscar: So tiny in fact they ship in prisoners from different countries to fill up there jails

Charlie: And there prisons are like you know, not bloody torture houses. So anyway Matt hancock obviously thinks that king of treatment is acceptable for criminals. He could have said that disabled people are being treated like there not human, which is true. But he thinks that that treatment is acceptable for criminals so that's just a little bit of background.

Oscar: and also, One last thing on the issue of the state of prisons is that if prisons are abusive, violent places, which they currently are where abuse is allowed to happen and people are left without medical care of course no one is gonna be able to be rehabilitated because that environment will only produce more abuse, more violence, more ill-health. Its quite simple

Charlie: yeah, more trauma, it's ridiculous.

Oscar: You can't expect people to go through that and come out and you know.

Charlie: so can we trust the government to do anything to change this? In 2017 something called the winterbourne scandal which happened. I think it was called Winterbourne view. [Sound of water] Don't worry Oscar is pouring himself some water he's not weeing in the corner of the room. Though I guess that would be okay. You know free love. No it wouldn't we're in his sister's house, if he started weeing on the floor that would not be cool. Anyway, the winterbourne scandal something which happened in 2011, it was, ill link some articles so you can read more in depth about it if you're so inclined. But basically it was one particular centre called winterbourne view hospital i believe and it was one of these ATU assessment treatment units where people are meant to go just for as short period of time when they are in crisis, to figure out how to help with these challenging behaviours in air quotes and then go back to their families and their families are meant to be given help to help live in the community but that's not what's happening some people are living out their entire lives in these places. Winterbourne view was found to be abusing people on horrific levels there was an undercover BBC Panorama tv show which if you're not from the UK, the BBC Panorama they obviously do undercover investigations normally like someone will get a job at one of these places and have hidden cameras this one there was also a family who had put a hidden camera into their grandmas' room I think. Anyway serial abuse was going on there and loads of people were arrested and it was shut down.

Oscar: I remember that

Charlie: and from that the government it was meant to be this moment of awakening, the government did this thing called “transforming care” and it was meant to massive initiative where they meant to basically as much as possible getting rid of these assessment treatment units, getting people back out of these places and getting them back into the community and improving care in the community and the slogan was homes not hospitals and basically this didn't happen. There is an article in the Guardian MAY 2018, so may of this year, seven years on from winterbourne view, why has nothing changed? Is the name of the article. And I just want to read one of the figures. “A government investigation and official report promised that lessons would be learned and committed to transfer the 3,500 people in similar institutions across England to community-based care by June 2014.” So were now four years on from their deadline as of April 2018 official figures show that “[more than 2,000](#) learning disabled or autistic people are still living in such units.” So most of the people are still living there, nothing has changed as Theresa May would say.

Theresa May: Nothing has changed...nothing has changed.

Charlie: So can we trust the government to do anything now? I mean, Matt Hancock, hasn't mention the transforming care initiative he's just asked that we look into specific situations and if we look into matt hancock a little bit more can we trust him? SO matt hancock has been in the news a lot for his opinions on health care. He is the health and care secretary. So he's not the full health secretary. Who is the health secretary now?

Oscar: I don't even know...

Charlie: It's changed so much, look it up look it up

Oscar: Isn't it Michael Gove? No he's the environment...

Charlie: We're normally really good at this but it changes so often at the minute it's really hard to keep up. Stephen Hammond

Oscar: yeah yeah, because it was jeremy hunt, then it was stephen barkley then dominic raab became the brexit secretary then he resigned so Stephen Barkley became the Brexit secretary so yeah Stephen Hammond is the Health minister.

Charlie: So i'm just skimming through the transforming care national response to winterbourne view hospital so this was a report put out by the government at the time of the winterbourne view scandal so I guess 2011. And the minister of the state care and support was a guy called Norman Lamb and he makes a little statement at the beginning of this about how horrific the situation was and about how things needs to change. And things need to change as a result of this panorama BBC piece and one of the things he says which is really interesting is "we should be no more tolerant people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment. This is why I am asking councils and clinical commissioning groups to put this right as a matter of urgency." Firstly, he said that put it right as a matter of urgency. Seven years on most reports and articles is saying nothing has changed, there are still 2000 people living in these situations and they are just as problematic and abusive and inhumane I guess. And secondly the example of Cancer he gives is so telling. So we should be no more tolerant people being placed in inappropriate care settings than we would people receiving the wrong cancer treatments. Cancer in the UK, probably in other countries is seen as, if you have cancer, it should be solved, you're put on a two week pathway. And I agree with this by the way. Cancer kills with a lot of people and it can kill people really quickly and it can go unnoticed so I agree with the amount of importance put on it but it's just interesting with an issue that affects so many people is seen as so important but it they can get away with not taking your issue seriously, even though it could kill you as fast, or as horribly violently or give you as much trauma or whatever, if it doesn't demand the attention of many people they will try and not give it the same amount of importance. Which brings me to a really fantastic quote from Tony Benn for who those of you who don't know was a left wing Labour Mp for 51 years who was basically the voice of the radical left for a while in the UK. When did he die?

Oscar: He died not long ago but I would say voice of the radical left in parliamentary politics.

Charlie: Parliamentary politics sorry. I really really adored him. And I don't know when this quote is from but its about refugees. "The way a government treats refugees is very instructive because it shows us how they would treat the rest of us if they could get away with it." And I think that this is so applicable to this situation. People with learning disabilities who are maybe more vulnerable and maybe don't have more of a say and can't make their issues known potentially as they are not in positions of power. They can get away with treating them this way so they do. The same with refugees, the same with anyone who's not in a position of power, if they can get away with treating you this way they will. And it goes back to these victorian morals and victorian ideas of the power at the bottom of the scale being treated like dirt.

Oscar: and you said there were 2000 people in these ATU's

Charlie: it's a lot of people yeah

Oscar: imagine following lamb's analog between cancer patients receiving the incorrect care, if 2000 people it had transpired were receiving the wrong care, the health minister would have to resign because that would constitute a scandal that would be all over the news. It would be "this is outrageous" how could this of happened?"

Charlie: Everyone would know about it.

Oscar: that you've effectively endangered in many cases these peoples' chances of recovery or of survival.

Charlie: and to further contextualise it cancer is given priority in legislating for health care. Cancer waiting times is always seen as a really important thing because it plays to the voting public and just to give an idea of how serious the crisis in the NHS and in the whole UK for social care and health care, an article from september 2018 so two months that cancer waiting times are at worst level ever in England. So if the medical problem which is at the very top of the importance scale which we know it is because he has just given the example of it is in this much of a state think about the people who are given the least amount of power and the least amount of thought, the most vulnerable people, the people with rare diseases, the people with learning disabilities that might not have be in power positions to speak up, can you imagine the situation they're in? Well it's not good.

So yeah, can we trust the government to do anything about it now? Well... Matt hancock just to give you a little bit of an idea about this guy is about. He is the secretary for health and care. If you look up matt hancock on Youtube and you watch interviews with him. His basic stance is people need to take better responsibility for their own health care. That's kind of his stance for you know if you're overweight you need to eat less, if you have an alcohol problem you need to drink less. It's a very uncaring, very like, the responsibility is your own.

Oscar: It's almost like quasi libertarianism, not to say that he's a libertarian in anyway but it's kind of that it is definitely the responsibility of the individual, the state should'nt be held responsible. But then it kind of begs the question

Charlie: why is he that minister?

Oscar: if he doesn't want to do anything about what his job remit...

Charlie: Okay give him the benefit of the doubt

Oscar: Okay

Charlie: there are some areas in which this works, we know that in terms of smoking this is the example he likes to give, in terms of smoking the government putting tax up on cigarette and putting those

Oscar: health

Charlie: health warnings

Oscar: the pictures

Charlie: I don;t know if you have this in the US, but in the UK we have pictures of like rotting lungs or like I don;t know

Oscar: They're pretty graphic pretty visceral

Charlie: pretty graphic horrible medical pictures on cigarette packs just to like shame people which I think is pretty grim but they've also kind of worked but I don't know where to start with that. But is he the right person for the job? He is so often a kind of a victim blamer and I don't want to put people in the weak position of being 'victims' but so many health issues are so beyond our control and so many health issues are of a direct result of government problems There was a study linking childhood obesity linking it to bad the environment, linking it to pollution and pollution areas there's so many things. And also he says it's the responsibility of individuals to make their health better well the government needs to legislate on making healthy food affordable because in this country healthy is not affordable, if you want to eat organic, if you want to eat free range, if you want to eat fish its expensive. The reason that people have bad diets is because everyone's skint. And for americans who don't know what that means, it means poor. People don't have money for these things

Oscar: You're obviously gonna go buy some frozen food that can feed your family for a week which which perhaps unhealthy rather than buy for the same price buy a meal that could feed your family for one night. IF you've got 50 pounds to spend that week.

Charlie: some people don't even have that... You see people , more and more often now you see people at the supermarket literally counting out their coins for tin food because they know that tin food is gonna keep its the cheapest, its the most filling. Beans will feed your families stomach. A fancy little piece of fish that costs....

Oscar: 7.99

Charlie: your day's budget or your weeks budget its not gonna fill your family's stomach. I guess when he comes out with statements about people needing to take better care of their health care its just wiping his hands of the situation. Not taking any responsibility for the situation and not wanting to see that actually there are a myriad of factors that go into somebody having poor health. Poverty is a huge one. Poverty, bad environment. ANd also what is brexit gonna do for access to good food because we know that loads of the legislation that keeps our food healthy is potential gonna go

Oscar: we're gonna be eating bleached chicken

Charlie: well yeah there was that whole bleached chicken story. Because the EU legislation on healthy food regulations. Anyway

Oscar: you digress

Charlie: I digress, i think i've kind of rambled. But the basic story is that assessment treatment units are meant to be places where people were to be assessed for challenging or dangerous behavior and then brought back into their community or their home with extra help. They have not been running like that for a long time and for 70 years activists have been calling them out and still we have 2000 people living in these places living in isolation, often going without health care often being abused often not able to see their family often being fed through hatches often being abused by each other and matt hancock is the guy who has recently said we've got to do something about this ignoring the fact that eight years ago the winterbourne scandal was meant to be the turning point and still it has not changed and this transforming care commission has not worked there's still 2000 people living in these situations. So be aware, i'll add loads of links, just know that it's happening be ready to sign petitions be ready to tell people about, be ready to make some noise. Oh and I had another little article just to add to the kind of situation for people with learning difficulties and disabilities in the UK there is a guardian article exploring 13 people who died due to poor chare in the NHS and some in these treatment centres and this brings me onto something else i want to mention if Oscar doesn't mind. I've been thinking about the power of diagnosed I guess. Once your diagnosed by the NHS system that is stored on your

file. And i know from going from hospital to hospital and having to get print out that things that have happened to me in my life or that ive been diagnosed with that maybe I don;t want to be informing every doctor that sees me are still at the top of my file as significant historical events that happened maybe ten years. And so OScar has been seeking out a diagnosis for Autism. We both know quite a bit about autism would you say?

Oscar: Yeah

Charlie: and we're are both pretty convinced that you have autism are we? And we naively thought that maybe that could be a really positive thing you know just that people are aware in the future for jobs and university and having my diagnoses we've kind of realised that's maybe a pretty naive perspective to start from. Oscar is an adult, he's out of education at the moment, he is managing his own kind of What would you call it?

Oscar: Life [Laughs]

Charlie: He's managing his own life

Oscar: If you could call it that

Charlie: and although all the kind of ableism and lack of decent access in a variety of situations causing him a lot of stress, would interventions from a system that's broken help that? And the thing that i've been thinking about in the same way that the things on my file which inform doctors negatively toward me, could this cause a massive problem for him? We know that. Oh Oscar is mixed race by the way. His mother is jamaican, so he is a mixed race man in a racist society and we are disabled people in an ableist society. Happy times babe. And I'm a woman in a sexist society so you know, all is good. I'm filler busting whilst I look for my notes. Okay, so this is a quote from the government website on people who are detained under the mental health act. We know that there is a lot of racism in mental health treatment in the Uk, This is the quote: "among the broad ethnic groups, people in the Black ethnic group were the most likely to have been detained under the Mental Health Act in 2016/17, and people in the White ethnic group were the least likely to have been detained among the specific ethnic groups, Black Caribbean people had the highest rate of detention of all ethnic groups for which ethnicity was reliably recorded". So what I'm worried about, or do you want to take over? So what i'm worried about is if Oscar has on his file oh yeah he has autism and we live in an ableist, racist society and something were to happen, say he was mugged or attacked by a white person, I can just envision a situation in which all of this gets twisted around on him and he ends up being detained. I don't foresee that happening, I don't think we go out enough for that to happen, I don't think were in the community enough for that to happen.

Oscar: [Laughing] don't worry we'll get our house bulgured and somehow I'll end up getting arrested.

Charlie: Well this is it. Obviously in america where they have guns. Obviously racism is on your mind all the time, but the way you have guns in america the violence is so much more obvious, you can go out into the street and get shot and that's scary. But in the Uk it would really have to escalate and there are loads of incidents of black men being killed by the police in the Uk, being beaten or whatever, there are loads of incidents still happening, loads recently this year and last year. So the other day Oscar was outside putting the bins out and we noticed that there was a police helicopter going above and it was one of the first times that I've really been like, oh shit I don't want you outside right now and I called him and said can you come back inside please. Because you can just envisage it, you know being picked out by racist police, this is the guy, the person they're probably looking for is a short woman or something. But I'm just saying, racism. Having something like this on your records can it be really used against you? Can you be treated like a criminal in inverted commas like Matt Hancock said because the government has knowledge of your disability or neurodiversity. Thoughts?

Oscar: I am in agreement. Because all of these things, a catalogue of diagnoses could be used by people or presented in away to prove your unreliability.

Charlie: That's it, it's the unreliability because sadly it's not something I wouldn't have even think about until I was trying to get my own health care diagnoses, and I wasn't being believed because I had depression or things had happened to me in the past that would be called a trauma I guess, so my health care for years and years and years, my health problems were assumed to be as a result of trauma rather than as a result of a genetic condition in which my body is falling apart and if had been diagnosed when I first became ill or when I first started showing symptoms. Instead of years and years and years later I probably wouldn't be as close as I am to needing a life saving operation as I am now. So it's how you're proved to be unreliable by the things doctors read about you or in another situation that the police might be able to read about you on your medical files for whatever reasons. So it's something to think about in relation to that. So I think we've kind of covered that in a rambling, kind of conversational way. We're trying the conversational thing. So we'll move on to out something positive. Shall we. So am I going first or are you going first?

Oscar: I don't mind. So, my...what do you call this section?

Charlie: Something positive

Oscar: something positive! is I learnt something today, well this week on Twitter, that Harriet Tubman who was an amazing individual who helped free herself and other slaves during american slavery, I found out that she was disabled due to a violent attack by a slave owner who I think threw a two ton metal block at her head so she was neurodivergent. ANd I guess one of the things we would like to do in this podcast is the intersectionality

between disability, race, gender and all these other things...sexuality. And not many people know this, so in the black community and in the wider community most people in England will engage with Harriet Tubman in the context of black history month but I think that's a really interesting thing about her, that she was disabled and I don't think many people know that. So check it out, just google NOS magazine Harriet Tubman disability and a really brief but interesting article on that should come up. And you say I can recommend a book?

Charlie: You can but I haven't done my something positive.

Oscar: Oh

Charlie: We do something positive then we do recommendations.

Oscar: Okay

Charlie: But i've just thought about something that you could recommend in relation to that. So my something positive is that I wanted to mention a new magazine it's called OUTLND and it was started by a group of goldsmiths, goldsmiths is a college of the university of London, in the Uk journalism MA students but most of them are professional journalists already and it was started by a woman called Ella who's the editor who's awesome and it is like a cool magazine for disabled people. There a few UK magazines for disabled people or about disabled people or stuff to do with disability and apologies if you're one of them. But they don't look like a super cool art magazine looks. Whereas this magazine is about artists and activists and influencers.

Oscar: [Cross talk] which is okay because non-disabled people have uncool magazines about fishing and gardening hey I love gardening by the way and they also have magazines like...can we name drop?

Charlie: I don't know

Oscar: Other magazines such as art magazines and literary magazine

Charlie: Oh yeah! I'm sure...I guess like Aesthetica is cool theres cool people

Oscar: or Freeze Mag, so yeah.

Charlie: this is a disability magazine uplifting up the voices of people with disabilities, artists, influencers, activists and it would look at home in the Tate Modern magazine shop.

Oscar: [Laughing] No where else, just only in the Tate Modern magazine shop

Charlie: No I'm just saying if you've been to the Tate Modern, if you're not from the UK, you may of heard of it, it's a big modern art gallery in London and....

Oscar: Mate! Might of heard of it? It's only like the most visited museum in the world

Charlie: Oh I'm sorry we met your friend who had never heard of Big Ben

Oscar: She wasn't my friend

Charlie: So I'm not gunna assume. She's very nice though. I'm not gunna assume that people have heard of it when they may not of heard of it.

Oscar: No sorry, it's not the most visited, it's the most visited art museum....

Charlie: Anyway it's got a really cool magazine section.

Oscar: I'm pretty sure....I'm gunna google it.

Charlie: So the positive bit of news is that it is not ending and they've all finished their course and it was essentially what they got marked on and it's not ending at that, its continuing.

Oscar: I was wrong, sorry can we start this whole segment again?

Charlie: The whole segment?

Oscar: I've just interrupted now.

Charlie: no no no, tell me what you wanted to say.

Oscar: No I said something wrong. [Mumbling] It's the sixth most visited museum in the world.

Charlie: Oh correction it's the sixth most visited (*Its not) So OUTLND is going to continue, they are applying for funding which if they don't get will be a travesty because they should. We might contribute to it, which is not confirmed and even if we don't get to contribute to it still want to sing its praises because it's really really good. To follow you can go to their instagram or their Twitter which is @OUTLNDMAG which I will put in the notes or OUTLND.Co.uk. So that's where you can keep up to date with them and if we do get featured that's where you'll get to see us, or if you're an activist or an artist or a writer I'm pretty sure they have details to submit and they also include poetry so do it do it do it. So that is my good news. Now you wanted to do a recommendation?

Oscar: Yes

Charlie: We have recommendations now.

Oscar: Even though I've had this book a while and I've been reading since it's been beginning to get dark a lot earlier and it's by Kaveh Akbar who is an Iranian-American poet and it's a collection of poetry called "Calling a Wolf, a Wolf" and yeah, shout out to Kaveh. Oh nice tidbit! We were meant to go a reading when he was promoting the release of this book

Charlie: Oh yeah

Oscar: a tour and on that night we had tickets and what not and we were unable to go to the book reading

Charlie: I was too sick

Oscar: too sick, so Charlie tweeted "ah we're really upset that we're unable to go" [laughing] and he responded going oh, i'm so sorry about that like give me your number and i'll like phone you up and read you some poetry

Charlie: Which was lovely and I believe completed genuinely

Oscar: yeah, he's a great guy.

Charlie: And if I wasn't completing shy and ermm.

Oscar: Insecure

Charlie: [Singing] Insecure don't know what for. So if I wasn't totally insecure and shy I would have definitely taken him up on it

Oscar: So Kaveh if your listening, we'll answer the phone next time

Charlie: He won't be listening but he's super cool, yeah, you should follow him he does super cool stuff

Oscar: and he recently completed his Phd so props! Props to you.

Charlie: and though it's not specifically disability related, the fact that he would call up. So he's all about that accessibility. He's all about that.

Oscar: Yeah so if you're interested in poetry about processing alcoholism, loneliness, regret and religion and your identity in relation that, check out Kaveh as he's an amazing poet and all round top human being.

Charlie: I have two recommendations, the first one is my own recommendation. The second I would say is an equal recommendation because we both have seen it. The first one which people may have already read as I think she published it last year, is a book called "Ask me about my Uterus" by Abby Norman who is an American Human being and it's a memoir. She has endometriosis and other complicated health problems and it's a really good memoir that I felt that I could really relate to. I have endometriosis thought that is not my main problem but she researches her health and is really up on medicine and knows that something is wrong with her and she's being discredited and you know it just goes through that whole process and it also talks about her home life. And the reason I am able to read it now because the audio book just came out and you can get it on Audible, am I allowed to say that? Audible, sponsor me.

Oscar: well yeah... if the sponsor

Charlie: [Cross-talk in an american accent] Sponsor me Audible

Oscar: Might need to improve that accent

Charlie: Approve my advert....and she's reading it and I love when authors read their own books and I think her voice is really Lis-in-able. So yeah, "Ask me about my Uterus" Abby Norman the audiobook on Audible. She also has a podcast called like Googled that or something, can you check?

Oscar: Do you want me to google that?

Charlie: Which is short segments on a piece of interest, something that she googled. Because she's a What's the word when you're really into like knowing things, information, she's a.... Anyway I can't think of it right now. I think she's just a bit of a self taught genius.

Oscar: [Mumbling] like an autodidact?

Charlie: Yeah maybe something like that. And the last thing I'm recommending is...

Oscar: Abby Norman's podcast is called "Let me Google that!"

Charlie: Let me google that, so if you just want something short to listen to. SO there are these two women who are based in the UK and they call themselves the triple cripples and they are, they do like short videos and they are women of colour is what they refer (to themselves) and they are disabled. ANd the reason they call themselves the triple cripple is because they say they're are black, they're women and they're disabled. Three points of oppression and I think they're trying to reclaim the word cripples and they do short videos together.

Oscar: And they're really funny.

Charlie: and they're really funny, The talk about things that are very true about disability and racism in the UK but they talk about it in a really really funny way and they're just really likeable

Oscar: Unlike us

Charlie: Yeah unlike us....[laughing] You can find them on twitter at @triplecripples and i'll put links in there to all there stuff as well. Would you say that's it?

Oscar: Yeah I need the toilet now

Charlie: I don't remember the sign off. Everyone just hold on

Oscar: I don't have to be here for this bit. ANyway see you later

Charlie: you do have to sign off just wait.... Thanks for listening to patients podcast, I produce and edit the podcast with...

Oscar: me

Charlie: Oscar Vinter, my wonderful partner who composed the intro and outro music. You can follow him on instagram

Oscar: @Oscarvinter

Charlie: oscarvinter and on Twitter at

Oscar: @vinterpoet

Charlie: and you can follow me on both instagram and twitter @charliejfitz and the website if you want to find the transcription or the show notes is Sickofbeingpatient.com. Thanks for listening, see you next time.

Oscar: See you later.

Charlie: Bubbye....Bubbye...Bubbye.

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