

Twitter Thread by G Peters



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@mssinenomine



1/ I have a thoughts about this thread critique of #DoctorsAreDickheads and to lesser extent some of the other criticisms I've seen or heard about it.

Thread ahead. It's gonna be a long one so buckle up or mute accordingly.

If the goal is for doctors to do better, let's use a hashtag that communicates an emphatic request for change - e.g. #DoBetterDoctors - rather than a proclamation of the inherent awfulness of doctors. 12/

— Kimberly Acquaviva \U0001f3f3\u200d\U0001f308 (@kimacquaviva) October 25, 2018

2/ First - etymology of the hashtag (as I understand it). @stevieboebi posted a video about how after years of misdiagnosis, dismissiveness and all the all too familiar to many of us experiences with doctors, she finally got a dx. (Note no hashtag). <https://t.co/f6XTcFTq2Y>

NEW VIDEO!

My biggest secret: I'm disabled. <https://t.co/PnrxUI9hxp> [pic.twitter.com/mgHEGbb1Qr](https://t.co/mgHEGbb1Qr)

— Stevie \U0001f52e (@stevieboebi) October 22, 2018

3/ At the very end of a *12 minute* video she makes a statement of support to people who have had or are having similar experiences struggling to get diagnosed and treatment. Doctors are dickheads were three words in a TWELVE MINUTE video.

4/ In response someone (not sure if they are a doctor or med student or what) said they are "personally offended" by those three words (and apparently missed entire point of video). @stevieboebi replied. <https://t.co/QG4hncz2Qs>

YEAH WELL SORRY FOR YOU but we are told to trust doctors fully and that HURTS PEOPLE because doctors have biases and they are wrong just like the rest of us humans. And me learning that helped me tell my doctors off and demand to be treated differently and led to my diagnosis.

— Stevie \U0001f52e (@stevieboebi) October 22, 2018

5/ At some point @crippledscholar tweeted.

<https://t.co/H1nmoykBy6>

I kinda want to see #DoctorsAreDickheads trending with stories of medical gaslighting and abuse <https://t.co/YO5vRtth8h>

— Kim Sauder (@crippledscholar) October 23, 2018

6/ #DoctorsAreDickheads was not the product of a think tank. It was a shout when told to shut up. And it hit a nerve. For what should now be obvious reasons.

7/ Second thing, before discussing the 'this is bad strategy' argument, is people need to wrap their minds around what happens when you are misdiagnosed or dismissed by a physician.

8/ For me I was seriously ill (doctor later admitted I was dying) in a major city with a medical school and multiple hospitals and specialists. I was desperately seeking help and was getting none NOT because no one *could* help me – because no one *would* help me.

9/ It is impossible to convey the feelings I felt in a tweet. Imagine dying of dehydration surrounded by fountains but the fountains are locked and have guards in front. In that case at least you could attempt sabotage. How do I make a doctor be a doctor to me?

10/ Likewise the time I had a PE & DVT & kept being sent home from ER without a single test. Days – I spent days – trying to get help for a condition that was predictable if they considered my situation. I could have died from and it left my lungs permanently damaged as a result.

11/ And I know my experiences are not that uncommon. Are these things aren't even recorded anywhere. No one I know of is tracking data on how many times I was turned away or all the mocking and belittling and harmful things that were said to me.

12/ Café I used to frequent near one of my old jobs was owned by POC (relevant info re healthcare experience). They went to their GP, walk-in, 2 ERs before their son - their child - was dx'd with partially collapsed lung. Imagine feeling that powerless as a parent.

13/ OK the truth is you can't imagine. You can only try to imagine and you will not come close to understanding.

14/ This is how I felt - I KNEW I was in danger. I KNEW I needed medical intervention and I couldn't get it. It is throw chair through a window level frustration – I didn't but it is literally that level of 'HELP ME YOU FUCKING FUCKHEADS!'

15/ And you know what stops you from throwing that chair throw a window? (Besides knowing being arrested won't help situation.) They are doctors and you have been taught since birth to listen to their judgment even if it conflicts with what you are directly experiencing.

16/ The internal struggle that goes on. The debate in your head between what you know because you are experiencing it and what the experts are saying. Do I fight them or myself? And then how it feels when after it all you find out you were right. No apologies. No accountability

17/ But you don't have to be in danger of dying to be damaged by doctors. I think I was probably less harmed in some ways in those situations because panic sets in and you fight to survive.

18/ The slow, constant beating down you go through in trying to seek help for the, at that moment yet to be diagnosed chronic or degenerative condition - that is lethal. It is agony. It is wearing down until you wonder which is worse - not getting help or another doctor visit.

19/ And it's not just that the act of being told what you are experiencing you aren't experiencing – a mind fuck for sure – it's that bc of the power they wield, the god complex they hold, they don't *disagree* – they are right and you are lying or 'crazy.' You are fake news.

20/ A doctor graciously inviting you to seek a second opinion is something you see on TV. Their word is THE WORD. This is the not science.

21/ Science is curious. Science is humble. Science takes in new info even if it conflicts with existing thinking. This is The Word. They aren't Moses, they are the finger that inscribed the tablets.

Better pray what they write is right.

22/ OK so *now* let's talk about this criticism of whether #DoctorsAreDickheads is 'good strategy' and whether we would be better served by 'Doctors do better' – perhaps with a pretty please on the end?

23/ First a reminder that this wasn't a strategy. No think tank. No PR firm involved. No meeting of disabled and chronically ill folks plotting to take down doctors.

24/ Warms up fingers for strategy discussion. This is part I really want to discuss and fear I won't do it justice in a thread but gonna give it a shot.

25/ OK first of all, let's assess the situation. I've laid out the players. So here's my assessment. I am showing up to the pro poker table with one chip – factual truth of my experience. Some places see this as a big money chip but they don't recognize its value. I'm out.

26/ The thing that regularly blows my mind on repeat with some 'progressives' is they want me to sit down and negotiate with zero leverage. There's a reason people go on strike.

27/ Little reported on fact – being on strike is not easy for the people who are on strike. But it's because that is what gives the people who are negotiating on their behalf any basis for being at that table with the people who hold the chequebooks.

28/ 'Doctors Do better' is a strategy based on politely and nicely pleading to powerful people to be give us a seat at *their* table because...because why? What is their motivation? Because they'll just want to be nice? Clearly that's not the case or there wouldn't be a hashtag.

29/ Certainly not all doctors – we know not all doctors – and maybe some doctors really will put in untold extra unpaid hours & labour, humble themselves, risk the scorn of their colleagues and jeopardize their careers – but ahem – can we talk systemically & realistically please.

30/ Awards banquets are in another line. I know there are heroes. I get middle-school level oddly nervous when I go see the doctor who finally listened to me and saved my life. I have been working on a gushing letter to his family.

31/ I figure people's spouses and children should know how extraordinary the person in their life is. And you know what. I don't have many letters to write and I have seen A LOT of doctors because my diagnosis has affects many parts.

32/ But at a systemic level physicians hold incredible power and what's more, unlike others with power – politicians, lawyers, bankers, corporate CEOs – doctors are perceived as being above reproach by the general public. Heroes. Sacrifice. Moral beings free of bias.

33/ This is huge because it means when they abuse or misuse this power people either don't believe or make excuses for them. And not only do we hear it from others, some of us have to struggle with it in our own heads. They are given power with cherry on top of virtual impunity.

34/ Don't doubt that I doubted myself. Don't doubt that I wondered if I was losing my mind. Don't doubt that it wreaked havoc in my spirit & life. Friends quietly question - 'If you were really sick wouldn't the doctors do something?'
Ghosted. Struggling alone w no where to turn

35/ The concept of punching down is bad not because 'punching' (metaphorically) is bad but because punching down is bullying. Punching up can be liberating, reclaiming of power and necessary and not just as a means to 'vent'

36/ Punching up and shaking that pedestal is usually necessary to get them to take a seat and take notes.

37/ Counts to ten but I still gotta swear here. The doctors coming into the hashtag pleading 'we're human' have some fucking nerve I tell you. Shout that at your colleagues about their patients.

38/ So to wrap this up. The hashtag wasn't a strategy but that doesn't mean it might not be strategically useful and from what I can see it played an role in bringing some folks together.

39/ There many variables involved in creating movement for change. The less wealth and power you have the less you control those variables. Truth is a powerful force and the reality is this isn't chess – or poker – this is people's lives.

40/ If you are arguing (well-educated) people (who call themselves scientists) in positions of power and privilege can't see past their hurt feelings, drop their defensiveness and open up their minds to exploring their bias and systemic injustice they participate in – I agree.

41/ Maybe the hashtag wasn't for them? Maybe they will only change if forced to change? Maybe they would come up with reasons to sideline any hashtag and any examples? 'Isolated' 'We're changing' 'He had a bad day'

That's my experience because I've done the polite work.

42/ I have volunteered for medical and health science students. I signed up for patient 'engagement.' I've sat on a hospital committee. I've attended conferences about physician leadership.

Here's some observations.

43/ I salute those who do those things but: a) not the most diverse group of people and the screening keeps it that way (no idea how I slipped through but specifically say no advocates allowed and this also works to make sure people censor themselves if they want to stay involved

44/ The patient perspectives you are likely to hear is not going to address systemic bias. The focus is on 'empathy' - and that's a thread for another day but I disagree. That doesn't address any of my complaints. None are based on me wanting more 'empathy' from doctors.

45/ b) That said I believe we all have a role to play. Some people sit on boards and work for quiet, polite incremental change and that matters imo. Some people protest and that matters. Some people write articles. Some people launch lawsuits.

46/ Some people write threads. And some people make Youtube videos to let other people know they're not alone and that the problem isn't them.

And when people with power leap in to say 'don't speak to us that way' you are proving exactly why we have to all of the above & more.