Twitter Thread by Dr Homeslice



Dr Homeslice
@8Homeslice8

The outrage is not that she fit better. The outrage is that she stated very firmly on national television with no caveat, that there are no conditions not improved by exercise. Many people with viral sequelae have been saying for years that exercise has made them more disabled 1/

> Why is it such a source of collective outrage that a person with fatigue following a viral illness gets better?https://t.co/5lcwQBPLU5
>
> — Trisha Greenhalgh \U0001f637 #CovidIsAirborne (@trishgreenhalgh) January 30, 2021

And the new draft NICE guidelines for ME/CFS which often has a viral onset specifically say that ME/CFS patients shouldn't do graded exercise. Clare is fully aware of this but still made a sweeping and very firm statement that all conditions are improved by exercise. This 2/

was an active dismissal of the lived experience of hundreds of thousands of patients with viral sequelae. Yes, exercise does help so many conditions. Yes, a very small number of people with an ME/CFS diagnosis are helped by exercise. But the vast majority of people with ME, a 3/

a quintessential post-viral condition, are made worse by exercise. Many have been left wheelchair dependent of bedbound by graded exercise therapy when they could walk before. To dismiss the lived experience of these patients with such a sweeping statement is unethical and 4/

unsafe. Clare has every right to her lived experience. But she can't, and you can't justifiably speak out on favour of listening to lived experience but cherry pick the lived experiences you are going to listen to. Why are the lived experiences of most people with ME dismissed?

And why are we painted as "horrible" when we speak up for our lived experience? None of the comments about Clare's interview were in opposition to her sharing her lived experience. They were in opposition to her making a sweeping statement that exercise helps every condition.

ME patients don't care if people recover. It rather, we WANT people to recover. What we object to is people extrapolating from their own experience and making general statements that what worked for them works for everyone, because it doesn't. Especially when they imply that if

we haven't recovered by the same means they have, then we must not be trying hard enough, must be too negative, must be militant anti-science activists or spending too much time in support groups. All of the above is unjustified and unfair to the hundreds of thousands of 1/

people with viral sequelae who are trying their absolute hardest to improve their health and to survive with a debilitating and highly stigmatised condition for which NICE clearly states there is no known treatment or cure. Yes, a small number t people do recover and we are 2/

happy for them. But the sweeping statements implying that exercise and positive thinking are the cure for everyone - they aren't evidence based. We don't object to them because we are negative and haven't tried exercise. We object because we have been trying those strategies 3/

for years, decades, and for the majority of us they either haven't worked or have made us worse. All we want is for our lives experience to be recognised too. It isn't. It is summarily dismissed and we are painted as bullies for speaking out in our own defence. We are patients 4/

in need of bring heard, compassion, acknowledgment, and most of all good quality science to find out what underlies the pathophysiology of ME/CFS and to find treatment options for the major for whom exercise therapy and positive thinking are ineffective. Even the PACE trial 5/

in its original published results, reported that only twenty something people recovered from combined CBT & GET. That means it wasn't curative for over 70% of people. The figures from th reanalysis according to the origin trial protocol are much lower for recovery ~7%. So even if

you think the original reporting of the PACE trial results was accurate, they showed that over 70% of people didn't recover from CBT and GET. This those of us who have been called "anti-science" for saying CBT and GET haven't worked for us, can't even justifiably be called

anti science, because our lived experience correlates with the findings published by the PACE trial authors which are that CBT and GET are not curative for the majority of patients. So why on earth are we being treated like horrible people for speaking up about this? Why aren't

you doctors able to see that even if you support the PACE trial, our experiences correlate with its results. We aren't anti-science, we aren't anti-recovery. We all WANT desperately to recover and live normal lives. But for that to happen we need acknowledgement of the fact that

as shown by the PACE trial, positive thinking and exercise are not curative for the majority of us, so we need a focus on finding alternatives instead of sweeping statements that "there is no condition that isn't improved by exercise" as Clare said on the BBC. We don't care if

she wants to share her personal experience. We are happy for anyone who recovers from illness. What we are objecting to is the incessant pushing of the narrative that positive thinking and exercise is the answer to all viral sequelae, and that if you experience otherwise your own

lived experience is invalid, and if you speak up in defence of your own lived experience you are an anti-science activist and a bully. You guys are doing to us exactly what you accuse us of doing to you. But there's a power relation because you are doctors & we are patients

So when it comes from you it's a question of professional ethics, which is really important. You need a very good justification for categorically dismissing the lived experience of hundreds of thousands of patients, and I don't believe you have one. Calling us bullies or

anti-science is not a justification. It's a deflection.

P.s. apologies for the typos. I hope you can understand what I am trying to communicate.

P.p.s. please also understand that our intention is not to bulky anyone. The reason tweets from ME patients are so numerous and sometimes strongly worded, is because we feel powerless. When high ranking doctors and professors have platforms like national TV to push their

narrative, we have no right of reply other than by speaking out on Twitter in the hope that our side of the story, our personal experiences, can also be heard. We don't do it to bully, we do it because we are fighting for our lives. That might sound dramatic but we are sick and

often powerless. We still get sectioned and forced to do exercise therapies that harm and disable us, and which have killed some. We are speaking from a position of powerlessness and fear, because the doctors who are supposed to protect and care for us do not recognise that they

are harming us. Twitter is the only forum housebound and bedbound people have to try to speak out for our own lived experiences, because for us it isn't a matter of politics, it's a matter of our safety and survival. That's why we are so vehement about it, and why there are so

many of us bombarding on this issue. Because we need to be heard otherwise we fear we will die under forced treatments that harm us, as others have done. And we don't want anyone to go through what we have been through. We don't have BBC interviews to share our stories, we aren't

well enough or prestigious enough to get media time whenever we want it. So the "hoard" of ME patients on Twitter is not a hoard of bullies that exists for no good reason. It's a thousands of patients in a desperate situation of neglect and stigmatisation, trying desperately to

be heard in a situation of immense power imbalance in which out lived experience is publicly dismissed and ridiculed by people with knighthoods, damehoods, professorships and various other leadership positions. The power imbalance is glaringly obvious yet little recognised.

And when you and Clare share tweets about the "horrible" tweets you've received, and all your colleagues reply saying "we have your backs", "ignore the trolls", "ignore the idiots", "ignore the detritus of Twitter", "ignore the scum", etc. They are speaking about PATIENTS!

They are speaking about sick people! Neglected people! People who are lying in beds hooked up to various tubes, unable to eat or move. They are speaking about some of society's most vulnerable. And calling the "scum", "idiots", "detritus", "trolls", "dregs", etc. In what world is

that an acceptable way to refer to a group of patients? In what world is that acceptable? But you allow it because you are promoting & allowing the narrative that we are just irrational Twitter trolls, not sick NHS patients trying to speak out about the harm we have experienced.