Twitter Thread by Peter White



Peter White
@mediumwhite

I held back from commenting overnight to chew it over, but I am still saddened by comments during a presentation I attended yesterday by Prof @trishgreenhalgh & @CIHR_IMHA.

The topic was "LongCovid, Myalgic Encephalomyelitis & More".
I quote from memory.
1/n
#MECFS #LongCovid

> Have you registered for IMHA's next webinar on Long-COVID? Guest speaker Professor Trisha Greenhalgh.
> When? Tomorrow: *Jan 13th.* 12pm ET
>
> A few spots are left, but going fast!
>
> Registration required: https://t.co/T4PbWNA35Y@KarimKhan_IMHA @CIHR_IRSC @trishgreenhalgh pic.twitter.com/xlWKi4QKF1
>
> — CIHR-IMHA Community (@CIHR_IMHA) January 12, 2021

The bulk of Prof @Trishgreenhalgh's presentation was on the importance of recognising LongCovid patient's symptoms, and pathways for patients which recognised their condition as real. So far so good.

She was asked about "Post Exertional Malaise"... 2/n

PEM has been reported by many patients, and is the hallmark symptom of ME/CFS, leading many to query whether LongCovid and ME/CFS are similar or have overlapping mechanisms.

@Trishgreenhalgh acknowledged the new @NiceComms advice for LongCovid was planned to complement... 3/n

the ME/CFS guidelines, acknowledging some similarities.

Then it all went wrong.
@TrishGreenhalgh noted the changes to the @NiceComms guidance for ME/CFS, removing support for Graded Exercise Therapy / Cognitive Behavioural Therapy. She noted there is a big debate about this. 4/n

That is correct: The BMJ published Prof Lynne Turner Stokes' column criticising the change (Prof Turner-Stokes is a key proponent of GET/CBT, and I suspect is known to Prof @TrishGreenhalgh).

https://t.co/0enH8TFPoe

However Prof Greenhalgh then went off-piste.

5/n

Prof Greenhalgh avoided acknowledging significant objective issues with the science underpinning GET/CBT: unblinded trials, subjective outcomes, and candidates not meeting current ME/CFS criteria (few/any trials required Post Exertional Malaise (PEM) to include in the trial).
6/n

Instead, @TrishGreenhalgh blamed the change in @Nicecomms guidelines on "aggressive" (I quote from memory) patient groups. She then identified a well-known friend of hers who did GET, and found it helpful.

Aside from ethical issues of naming patients, this is an n=1 case.

7/n

If I told my GP "my mate got better by doing X" I would be laughed out of the surgery. Why is that being presented as "evidence" to a @CIHR_IMHA audience?

Furthermore, @TrishGreenhalgh failed to mention Prof Jonathan Edwards' (not on twitter) Expert Testimony.

8/n

Prof Edwards went in to detail on the issues with the GET/CBT trials as part of @NiceComms' review.

His testimony can be found here:
https://t.co/qLhsBJ4Bcu

9/n

In blaming "aggressive patients" for the change, Prof Greenhalgh took fire not on the science, nor an academic equal, but on patients who, like LongCovid sufferers, probably just want to be acknowledged and recover.

I find this ill-befitting of an academic of her standing.
10/n

She is respected. She has a big platform, to use it to support non-science (n=1 cases) and blame patients is awful, and deserves criticism.

It puts her view in the field of politics not medicine.

That opens her to political-style criticism, which would be a shame.
11/n

There are other medics who have done that, and have become infamous for their poor pronouncements. I hope that @TrishGreenHalgh will not go the same way.

We must play the ball, not the player.

12/n

As for ME/CFS patients? Well, who needs research when they get better with graded exercise, right?

Perhaps that is why, between 2015-2016 only £5m / year was spent on researching the condition.

Or aproximatly £0.35p per person, per year. Ouch.

https://t.co/TUPEiSCLZq

13/n

As to “aggressive patients”, I do not know their story, but perhaps LongCovid and Endometriosis sufferers will sympathise with the pain of being dismissed?
It really hurts.

And how ‘aggressive’ were these patients? Is this tweet aggressive? Will I be blocked and blamed?

14/n

Why do I care?
I have a fatiguing gut condition and was mis-diagnosed with ME/CFS 4 years ago. I walked 6Km / day.

A specialist ‘undiagnosed’ me as I did not have PEM.

But in 2005, could I have been eligible for a GET study, and might have felt better after exercise.

15/n

I am not alone. A friend was diagnosed with #MECFS for a decade. It turned out she had Cushings.

She likes to go for walks, and exercises when she can. Had she taken up the offer to participate in a trial, she may have improved too.

16/n

Both would have erroneously supported GET & CBT, in spite of not having PEM or ME/CFS.

I also experienced gas-lighting from the 20+ docs who told me it was all in my head. Thankfully I now have much better medical support, but many struggle.

17/n

As fellow humans, we should support the sick.

The condition needs research, and that starts with belief, and develops with high-quality, objective science.

END/

@bendymarsh, @benh_mecfs grateful for your thoughts.

Addendum: Well, I have been blocked, and comments have been made.

I am actually a big supporter of Prof Greenhalgh's work. Masks are good. So is good patient care.

I have no malicious intent, but it is right to challenge bad pronouncements on this issue.



In my comment I have tried hard to avoid Ad Hominem or malice. Challenge is not malice.

If you think I have got it wrong, please let me know.

Please challenge misinformation about on ME/CFS, but accept that even great people make mistakes. Forgive.

People have a right to reply. She didn't reply to me, but this is her recollection of the discussion. I hope including it makes this thread more balanced.



Trisha Greenhalgh 😷 **#CovidIsAirborne**
@trishgreenhalgh

Replying to @feu_petit and @NICEComms

I was asked about fatigue in long covid. I said NICE LC guideline had deferred that aspect to the CFS/ME guideline which was currently rather controversial. I then tried to summarise 2 sides of the controversy. Said NICE had "been accused of" bowing to patient pressure. That's it

9:03 PM · Jan 14, 2021 · Twitter Web App