

TEN YEARS ON: “SOMEWHERE TOWARDS THE END”

Further explanation of my [blog post](#) of the same name from
September 2022

ABSENCE OF LEADERSHIP, LACK OF TRUST AND ZERO STRATEGY

In my recent post, "[The Poisoned Well: a history of ME in 20 tweets](#)", I set out a brief history of ME - how it came to be dominated by the toxic influence of what I term the "psychiatric lobby group" and how that influence became one of the most insurmountable obstacles to progress for the worldwide ME community. However, this is only one part of the story.

The other part of that story involves the worrying absence of leadership at the institutional and organisational level of the UK's ME community. There are many different charities and patient organisations - too many, some might argue - which has led to a lack of cohesion, transparency and accountability.

“Due process is very dull – but it matters”

Community representation has mostly been controlled by a cluster of three or four lead charities and, since 2008, the informal but powerful "co-ordinating body" known as [Forward-ME](#) (FME).

FME has no formal constitution or legal entity so there are no checks and balances on its activity or its finances. It has no requirement for accountability to, or mandate from, the ME community which it purports to serve.

It has an unelected chair who [retains control over who is, and who is not, invited to participate in its activities](#) which are apparently undertaken on behalf of the whole ME community in the UK. It is not a registered charity, so it is not subject to regulation by [The Charity Commission](#) nor is it scrutinised via any other external oversight.

Of particular concern, is the fact that patient/group inclusion in the activities of this cluster is frequently secured by patronage. It is hardly

surprising, therefore, that the level of trust that FME (and its invited members) receives from some long-term patients/advocates appears to be extremely low.

Democratic process is, by and large, non-existent. Inevitably, newer members of the patient community are rarely aware of this and so provide unwitting support to a flawed and entrenched system.

As I said in a [series of tweets](#) on this topic:

“Due process is very dull – but it matters.....FME's operations are opaque and its leadership unaccountable, a red flag in [the] third sector as there are no checks/balances in place. Such a lack of transparency cannot be in [any] community's best interests [particularly one with so many disabled and vulnerable members].” [paraphrased tweets]

This lack of leadership has enabled the continuation of a culturally toxic and damaging *status quo*. It has also ensured the continuing existence of an internally fractured and fractious community. This was particularly evident in [the NICE debacle of 2021](#).

The NICE debacle

In August 2021, NICE (the English [National Institute for Health and Care Excellence](#)) was due to publish the long-awaited update to its guideline for the diagnosis and management of the illness termed ["myalgic encephalomyelitis/chronic fatigue syndrome" or "ME/CFS"](#).

At the eleventh hour, NICE "paused" publication of the new document for completely spurious reasons. It transpired that this "pause" was triggered by [wholly improper external interference](#) by an extension of the psychiatric lobby group, composed of representatives from some of the [Royal Colleges](#) and [NHS England](#). As a result, the ME community was thrown into chaos and confusion.

NICE then asked the various ME patient organisations to collude in its failure to hold its ground and wait patiently so that it could all be sorted out through a roundtable process. NICE also decreed that the

unpublished guideline remained confidential, [a claim with which I strongly disagree](#).

At this time, I advised, both privately and [publicly](#), that the ME organisations should refuse to co-operate in this charade as they were on rock solid territory, both legally and morally.

The new guideline had already been circulated in confidence, two weeks earlier, to the stakeholders involved in the review process. Many organisations/individuals were already in possession of the document and could have made it available publicly.

The international ME community would then have had access to the disputed document and been able to monitor any further adjustments, although the guideline would not become operational until it was published by NICE.

Zero strategy

My advice was ignored. The ME organisations capitulated to NICE's specious requests. Patients, carers and healthcare professionals were left waiting with bated breath to learn the outcome of the now completely discredited NICE process of reviewing the original, [dangerous guideline for "CFS/ME" from 2007](#).

Almost three months of agonised waiting followed, during which time the organisations co-operated with NICE. The guideline document was diluted further, the original objectors withdrew to [plot their comeback](#) and the [doctored version of the guideline was finally published](#) at the end of October 2021.

Four weeks after the initial "pause", and before that final publication, I took a carefully calculated risk and made the "confidential" document available myself, so that the international ME community could have access to it if its members so chose. My post containing the reasoning behind my decision and a link to the original "paused" document is [here](#).

Eventually, [the new guideline](#) was published. Many would argue that everything turned out fine because it wasn't hugely different from the "paused" version (never published officially). I disagree strongly with that assessment for these reasons:

1) A weak and leaderless community

Yet again, the ME community looked weak and indecisive, lacking both leadership and direction. The *better strategy (below)* would have been for the community, acting in concert, to make the unpublished guideline available publicly then sit back and wait for NICE to sort out its own mess.

To do otherwise highlighted yet again the decades-long stranglehold which the psychiatric lobby group and its supporters have retained over all matters relating to ME practice and policy development, particularly in the UK.

The better strategy

If the ME community had held its ground, as I advised, the eventual outcome might still have been the same. However, the community would not then have been complicit in allowing the continuing domination of that particular lobby group over all matters relating to ME.

*Additionally, had NICE materially **altered** the guideline as a result of lobby interference, there would have been stronger grounds for ME community representatives to seek a judicial review of NICE's decision, as the community would have distanced itself from NICE's position.*

By collaborating with NICE, the ME community groups had potentially weakened their own future position, whatever the outcome.

2) The problem was for NICE to resolve, not the ME community

Last-minute resignations from the guideline development committee had already sent out warning flags that trouble might be brewing so this pathetic and desperate attempt at meddling in the process should not have been entirely unexpected.

There was absolutely no need to play nice with NICE. NICE had created the problem itself by failing to maintain its position therefore the problem was down to NICE, and NICE alone, to resolve.

3) A further diluted and even more unwieldy new guideline

Although the final published guideline (87 pages) was similar to the previous, unpublished version (83 pages), it had been diluted even further from the more acceptable draft of 72 pages, from November 2020, leading to a further loss of clarity and certainty.

Does the absence of leadership really matter?

Some may argue that none of what I have said above matters now because of the [announcement in May 2022 of the cross-government delivery plan for "ME/CFS"](#) by then Secretary of State for Health and Social Care, Sajid Javid. I assume that the introduction of this plan may have been achieved through the efforts of the same cluster of institutions that I have criticised here.

However, it is important to note that the “Attitudes and Education” and “Living with ME/CFS” working groups created by this delivery plan [have representatives from the Royal Colleges and NHS England amongst their invited members](#) (as well as other representatives who, historically, have not always served the ME patient community well). Yet both the Royal Colleges and NHS England were implicated in the last-minute interference with the 2021 NICE guideline process that caused so much chaos and distress to the wider ME community.

According to an August 2022 update, [the cross-government delivery plan continues to gain momentum](#) and is making its way slowly through the usual preliminary processes. It is very much a creature defined and controlled by civil service bureaucracy but it will, no doubt, move things forward for the ME community in the fullness of time.

So why is there still a problem? My response is in **two parts**:

1) History repeats itself

This cross-government delivery plan bears a remarkable resemblance to the ME Task Force set up in 1998 which created the [Department of Health working group on “CFS/ME”](#). This culminated in the publication of the [Chief Medical Officer \(CMO\)’s Report of 2002](#).

The CMO’s report was expected to resolve matters and finally change the situation for ME patients once and for all. I remember awaiting its publication with great anticipation. However, the report proved controversial with parties on all sides refusing to endorse it.

Then, in 2007, NICE published the [first guideline for “CFS/ME”](#) which recommended the harmful treatments of graded exercise therapy and cognitive behavioural therapy.

This was followed in 2011 by publication of the [PACE trial](#) which reinforced those dangerous treatments both within the medical community and, more generally, in the prevailing toxic narrative propagated by the psychiatric lobby.

As a result of those developments, media-generated perceptions of ME community members as the lazy, crazy, [and sometimes even dangerous](#), people have continued, often facilitated by the UK’s [Science Media Centre](#). The 2021 NICE guideline, whilst welcome, has so far done little to change this still prevalent zeitgeist.

And, of course, in 2022, it remains the case that there are still no accepted diagnostic biomarkers, treatments or cures for this illness. The current situation shows precious little evidence of real change for patients on a day-to-day basis since the publication of the CMO’s report twenty years ago.

2) There is still insufficient acknowledgment of the historical and political context

The second part of my response is contained in *two tweets (below)* from the ["Poisoned Well" thread](#) (*above*). The “damage” mentioned in the thread refers to that caused by the psychiatric lobby:

The Two Tweets (from May 2022)

“Recap: 1934 ME first documented. 2022 no tests/treatment/cure, minimal research/resources (compare LC [long Covid]), physical harm actively caused to patients over decades (gross negligence), reputational damage to already traumatised international patient community + still no acknowledgment...”

...Whilst both the recent statements by [@sajidjavid](#) [the then British Secretary of State for Health and Social Care] and actions by the [#ME](#) orgs are most welcome, this painful history is not being acknowledged on a scale which properly reflects the appalling and now irreparable damage caused to the patient community over the last 50 years.”

My broader point is that the lack of leadership and direction within the UK's ME community is also partially responsible for that damage because of its failure to act in a way which could have mitigated the continuing physical, psychological and reputational harm being caused to patients.

I have [set out in detail](#) how this could have been achieved in numerous blog posts, for example, in my 2019 series "[Changing the Narrative](#)".

So yes, leadership matters - and its absence matters even more.

CONCLUSION

Over the last fifty years, the UK's ME community institutions have continued to repeat the same mistakes. There has been a failure to grasp the role of leadership and seek appropriate professional advice in countering the toxic and all-pervasive effects of the dominant narrative, led by the psychiatric lobby and its acolytes.

Professional advisors should have been sought and fully briefed. They should then have been tasked with providing the groundwork for initiating an ongoing proactive communications strategy and the implementation of a wide-ranging media plan.

The plans should have been set at a suitably robust level with the long-term aim of securing a public inquiry into the institutional treatment of ME patients, their families, carers and those who support them.

“The history of ME remains one of the worst examples of unacknowledged institutional abuse in modern times.”

~ Valerie Eliot Smith 2019