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IS ELSEVIER GUILTY OF PUBLISHING MISINFORMATION ABOUT MYALGIC ENCEPHALOMYELITIS?

Margaret Williams 12th September 2025

Myalgic encephalomyelitis (ME) has been classified by the WHO in its International Classification of Diseases as a disease of the nervous system since 1969.

In defiance of such classification, for decades there has been contrived controversy about the nature of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in the UK. It is irrefutable that a small but influential group of mental health practitioners known as the "Wessely School" (known for being closely associated with the permanent health insurance industry and with the Department for Work and Pensions) has dominated the scene with their dictum that ME is not a disease at all, but a "*false illness belief*", and that "CFS" is a behavioural disorder amenable to psychotherapy.

Of note is the fact that throughout their literature, Wessely School adherents sometimes regard ME and CFS as the same condition and at other times as different conditions. Also of note is the existence of written evidence that the then-DSS (Department of Social Security, which became the Department for Work and Pensions) previously regarded ME as a long-term, serious medical disorder, distinct and separate from CFS, and the latter as a less serious, treatable disorder, until psychiatrists Drs Simon Wessely and Peter White persuaded the DSS to regard the two separate disorders as one-and-the same psychogenic disorder.

If the wealth of peer-reviewed published evidence proving the organicity of ME were to be heeded, it would destroy the Wessely School's model of "CFS/ME" as a functional (i.e. mental) disorder and would halt their continued denial of ME as an organic disorder. However, such is the influence and control exerted by Professor Sir Simon Wessely himself that this evidence has all but disappeared in the UK, as reflected in the latest edition of Kumar and Clark's textbook "Clinical Medicine" published in June 2025 (see below).

Despite many thousands of published peer-reviewed articles that comprehensively disprove their dictum and despite ME's formal classification as a neurological disease, the Wessely School's own "false belief" still permeates the NHS, with disastrous results. Because people with ME have been subjected to actual abuse whilst in hospital and have died as a result, more than one Coroner has had to serve a Coroner's Regulation 28 (Prevention of Future Deaths) Notice issued under Coroners' (Investigations) Regulations 2013, a Notice applicable to the NHS regarding prevention of future deaths specifically in cases of ME.

The Wessely School's damaging dictum about ME remains paramount throughout the Medical Royal Colleges, with the result that doctors working in the NHS do not want to "medicalise" ME by treating it as a physical illness, so patients die (see below).

The Wessely School dictum certainly influences UK Departments of State and the medical insurance companies, with the result that people unable to work due to ME are denied financial benefits to which they are legitimately entitled.

Disturbingly, the examination for membership of The Royal College of Physicians frames "CFS/ME" (as distinct from "ME/CFS") as a mental disorder.

For more information on this long-running saga (from 1986 to date), see https://margaretwilliams.me/ and/or https://www.oneagleswings.me.uk/margaretwilliams/

There is, however, an increasingly bright light being shone on the decades-long dark world of iatrogenic abuse of people with ME (PWME). In October 2021 NICE published its revised Guidelines on ME/CFS in which it revoked its previous support for the Wessely School's dictum and strongly advised against the use of their psychosocial interventions, acknowledging the copious evidence that their interventions -- their own brand of GET (graded exercise therapy) and directive CBT (cognitive behavioural therapy) – are harmful and, in particular, noting that the studies upon which the Wessely School relied in support of their own interventions are of "*low or very low*" quality. Unduly influenced by Wessely et al, the Medical Royal Colleges reject the revised NICE Guidelines, but in a meticulously presented article, NICE demonstrated that their revised advice is based on a thorough review of the

evidence, stating that "*Criticisms of the guideline discussed in this paper are misplaced"* (Barry PW et al: JNNP 2024: doi:10.1136/jnnp-2023-332731).

There has been considerable progress in demolishing the Wessely School's teaching about the nature of ME/CFS. Although there is substantive published evidence of the organicity of ME dating back to the 1980s, there is more recent published research that confirms the organicity of ME/CFS. For example, Professor Chris Ponting from the University of Edinburgh recently published an article in the EMBO (European Molecular Biology Organisation) journal Molecular Medicine: "Replicated blood-based biomarkers for myalgic encephalomyelitis not explicable by inactivity". A press release from the University of Edinburgh states: ***"The largest ever biological study of ME/CFS has identified consistent blood differences associated with chronic inflammation, insulin resistance and liver disease"***. The study found that individuals with post-exertional malaise (PEM – the hallmark symptom of ME) show stronger biomarker differences. Professor Ponting said: ***"For so long people with ME/CFS have been told that it's all in their head. It's not. We see it in their blood".*** He said the evidence should ***"dispel any lingering perception that ME/CFS is caused by deconditioning and exercise intolerance"*** (www.bbc.com/news/articles/cy8k73443g4o).

The publicity surrounding these findings cannot have been missed: one such is to be found at https://theconversation.com/ignored-blamed-and-sometimes-left-to-die-a-leading-expert-in-me-explains-the-origins-of-a-modern-medical-scandal-241149 and leaves an indelible impact:

"Ignored, blamed, and sometimes left to die – a leading expert in ME explains the origins of a modern medical 'scandal'.

"Worse, when we don't ignore them, we blame them, telling them that they are all free to rise from their beds and wheelchairs… Doctors tell them they can free themselves of the disease by changing their belief systems. Make the effort, they say, and you will regain your health and previous lives.

"Some lie still in their darkened rooms, masks on to protect them from their light sensitivity, keeping within their limited energy level, unable to tolerate sound, food and touch – lives spent in the shadows, barely lived. Inside, they feel like they have life-sapping toxins coursing through their veins. They say it feels like being on the verge of death; some even call it a "pseudo dying syndrome".

"A brief conversation with a friend, or washing their hair, or a sudden movement causes their symptoms to flare. This intensifies a fatigue that sleep cannot alleviate, and heightens their muscle or joint pain, headaches, or sensitivities to food, light or sound.

"A 'scandal' so much more than chronic fatigue: *Fatigue does not begin to describe this disease.*

"Treatment of ME has been called "the greatest medical scandal of the 21st century" by Guardian journalist George Monbiot. It is difficult to disagree when there is not a single bed anywhere in the UK set aside for treating people with severe ME.

"The Times journalist, Sean O'Neill, says that ME is "routinely stigmatised and ignored by the NHS" and calls it "a scandal waiting for its Post Office moment". O'Neill and his family had to endure the inquest into the death of his daughter, Maeve Boothby O'Neill, who died from severe ME aged 27.

"ME exiles people from their family, friends, and hoped-for futures. For most, this banishment is for life because nine in ten will never recover, and also because we expend too little effort to end this wicked disease".

There is published evidence of dysautonomia in ME, for example: "A global need for more awareness of dysautonomia in postviral syndromes" by long-time ME/CFS researcher Professor Julia Newton et al (Journal of Medical Virology, Volume 95, Issue 8, August 2023, e29048). For Elsevier to disregard the existence and effects of dysautonomia by recommending interventions that are impossible for those affected is a matter of considerable concern.

Another immensely important paper is from a well-known team of world experts in ME/CFS: Columbia University's Mailman School of Public Health is clear about the correct status of ME: "Heightened innate immunity may trigger chronic inflammation, fatigue and post-exertional malaise in ME/CFS**"** available at https://www.nature.com/articles/s44324-025-00079-w

Links referring to those findings are equally clear: see https://www.eurekalert.org/news-releases/1096511

"Once thought to be a psychological disorder, ***there is abundant evidence from studies of blood, muscle and brain that ME/CFS is a physical syndrome****…In ME/CFS patients (researchers) observed disruptions in interconnected pathological processes that are often observed in chronic inflammatory conditions, suggesting a state of metabolic dysfunction, immune dysregulation and tissue damage, potentially triggering a systemic inflammatory response"*

The findings of this study demonstrate:

- **Impaired cellular energy production,** which may lead to physical and mental exhaustion and the accumulation of toxic metabolites.
- **Lipid abnormalities** that contribute to tissue damage and perpetuate inflammation.
- **Disruptions to the extracellular matrix** which provides structural support and regulates cell behaviour and release of signalling molecules that promote inflammation.
- **Disruption of epithelial barriers**, particularly in the gut which can contribute to the development of gut dysbiosis, where the balance of gut microbiota is altered resulting in the translocation of bacterial products into the blood where they trigger inflammation.
- **Activation of the complement system of the innate immune system**, the overactivation of which can contribute to tissue damage, inflammation, and sustained fatigue.
- **Disturbances in copper-dependent antioxidant pathways**, which can promote oxidative stress, promote inflammation, and contribute to tissue injury.
- **Dysregulation of tryptophan-serotonin-kynurenine pathways**, which can lead to impaired cognitive function.

Notwithstanding such evidence (although the publication of this particular evidence post-dates the Elsevier publication in question), another douse of petrol has recently been added to the embers of the Wessely School's dying fire: in June 2025 Elsevier published its 11th edition of Kumar and Clark's "Clinical Medicine". To widespread disbelief, ME was firmly sited in the "General Hospital Psychiatry" section and, despite it having been exposed as unequivocally harmful as well as fraudulent, the PACE Trial was the "recommended reading" about "CFS". This is in stark contradiction to -- and defiance of -- the revised NICE Guidelines.

Such was the concern about the wrongful categorisation of, and advice about, ME/CFS in a major medical textbook that The Grace Charity for M.E. organised a petition asking Elsevier to issue an *erratum* (ie. a correction); co-signatories to the petition included The 25% ME Group; Tymes Trust; the ME Association; ME Action UK (and its affiliate #ME Scotland), all of them being registered ME charities, and also Doctors with ME, as well as over ten thousand other signatories in support.

The Grace Charity's *erratum* request asked that four issues be addressed:

1. That ME/CFS be placed in the Neurology section and removed from the "General Hospital Psychiatry" section.
2. That, in compliance with the WHO's classification, M.E. is correctly named as "myalgic encephalomyelitis" and not "myalgic encephalopathy".
3. That the author(s)' assertion that ME/CFS is in part "psychological" be withdrawn.
4. That the recommendation of the PACE Trial as further reading be removed.

The petition was submitted in early July 2025; on 1st September 2025 The Grace Charity received a reply from Elsevier, from which the following extract is taken:

"We have discussed your concerns in detail with the editors of the new edition, the founding editors of the book, and the contributors to the General Hospital Psychiatry chapter…This coverage provides an introductory overview tailored to medical students…Psychiatric departments have a well-established and significant role in managing CFS, and medical students are most likely to encounter CFS patients in this setting. Therefore, the inclusion of CFS within this chapter reflects current clinical practice in the NHS…Regarding your specific comments on the PACE trial, we believe it is important to leave it in the Further Reading section to encourage students to engage broadly with the literature and develop critical appraisal skills…However, we will address your request to include the term Myalgic Encephalomyelitis in addition to Myalgic Encephalopathy as a reprint correction…As an educational resource, our emphasis is on current treatment approaches…Our subject matter experts, who are actively involved in caring for CFS patients, agree that the current placement of the content is appropriate. Altering the placement of content solely to accommodate your request would compromise the educational integrity of the textbook. Accordingly, the content will remain in the General Hospital Psychiatry chapter…Thank you again for your feedback, but for this edition the topic is now closed".

Such a response defies rational belief.

Can there be any doubt that yet another generation of medical students is being taught to regard ME/CFS as a psychiatric disorder?

It is reasonable to believe that the consistent use of the term "CFS", not "ME" or even "ME/CFS", indicates Elsevier's mindset about the status of ME.

The authors of the 11th edition of Kumar and Clark's "Clinical Medicine" are David Randall, John Booth and Kate Wiles; all are qualified doctors. Medical practitioners, including authors of chapters in medical textbooks, have a duty to keep their CPE (continuing professional education) up-to-date, especially if, as confirmed by Elsevier, those authors are "*actively involved in caring for CFS patients"* and Elsevier ought to know this, so that the "*educational integrity of the textbook"* is indeed maintained. Sadly, this is not the case in the 11th edition of the textbook in question.

It seems to have escaped Elsevier's notice that the power of the internet to convey medical knowledge is greater by far than their textbook of medicine, so those who wish to "*engage broadly with the literature and develop critical appraisal skills"* can readily access up-to-date knowledge about ME, the plentiful opportunity for which appears to expose Elsevier's regrettable failure to do so.

Such apparent failure of Kumar and Clark's authors to keep up their CPE has undoubtedly caused significant reputational damage to Elsevier by including the long-outdated and disproven content about ME as *"current treatment approaches"* in outright rejection of NICE's revised Guidelines, so it would surely be in Elsevier's own best interests to provide an *erratum* without further delay.

There is concern at the highest level of UK Government about the lack of appropriate provision for people with ME/CFS and the harm to people resulting from Professor Sir Simon Wessely's machinations about the nature of what has now been established as a physical disease (ie. not merely a syndrome). By letter dated 18th August 2025 the Rt Hon Nick Thomas-Symonds MP, Minister for the Cabinet Office, refers to the effects of the Wessely School's dictum as "*these important matters"*.

Not only is there mounting concern in the UK, there is international concern about the Wessely School's extremely damaging and uninformed beliefs about ME/CFS and the consequential unnecessary suffering imposed on patients.

On 16th May 2025, the month before Elsevier published the 11th edition of Kumar and Clark's "Clinical Medicine", a book entitled "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Methods and Protocols" was published by Springer Nature (ISBN 978-1-0716-4497-3). The co-authors are Professor Warren Tate and Dr Katie Peppercorn from the University of Otago. It is a comprehensive guide for clinicians and researchers about ME/CFS and it brings together published studies from 48 international authors. It covers the clinical diagnosis, diagnostics, immunology, molecular biology changes in DNA, RNA and protein, metabolism and energy production. Research has expanded from the initial immunology trials to investigating what is happening in muscles, the brain, and the microbiome of ME sufferers, each author contributing different perspectives, which led to the identification of the disease.

Interviewed about the book, Professor Tate said: *"**Combining this large body of robust research into one publication validates for patients their illness**. **The people and their families who live with ME know it's a devastating disease** - the vast majority of those people can't work, some can't get out of their home, or even their bed. This book therefore sheds light on what they experience… Those who live with (ME/CFS) don't know from one day to the next what their health will be like. They experience a lack of understanding from other people, from insurers and even from GPs. **They often have treatments…which don't work or even make the condition worse…There was a massive inflammatory response which led to the brain not regulating temperature, blood sugar and gut responses, leading to a life of severe fatigue…We know there are biological causes and energy production is dysfunctional**. We see molecular changes resulting in dysfunctional physiology"* (9th July 2025: MedicalXpress: "Fight to understand myalgic encephalomyelitis takes a major step forward": https://medicalxpress.com/news/2025-07-myalgic-encephalomyelitis-major.html).

Can Elsevier's authors/editors really be unaware of this publication, or are they so committed to the Wessely School's discredited and invalidated ideology that they deride it?

Perhaps the most cogent concern about the Wessely School's decades-long control over all aspects of ME/CFS is to be found in the article "Why the Psychosomatic View of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is

Inconsistent with Current Evidence and Harmful to Patients". It was published on 31st December 2023 by Professor Carmen Scheibenbogen et al. She is Professor of Immunology and Deputy Chair, Institute of Medical Immunology, at the University Hospital Charité in Berlin (Journal of Clinical Medicine 2023:12(24)8345 https://www.mdpi.com/1648-9144/60/1/83). She does not mince her words:

"A vocal minority of researchers remains convinced of a psychosomatic…causation of ME/CFS despite the frequently demonstrated organic abnormalities and the simultaneous lack of evidence for relevant psychosomatic factors. The striking discrepancy between the strong conviction among proponents of a psychosomatic aetiology of ME/CFS and the simultaneous lack of evidence for this view has also been observed in other scientific fields. Research shows that…individuals who strongly disagree with the scientific consensus are, on average, less knowledgeable about the topics than others but are more convinced of their knowledge".

Professor Scheibenbogen continues: *"Contrary to psychosomatic hypotheses, replicable organic abnormalities are evident in ME/CFS. The most important replicated abnormalities include a significant reduction in cerebral blood flow, endothelial dysfunction, a reduction in systemic oxygen supply, a reduced peak oxygen consumption, an increase in ventricular lactate levels, hypometabolism and increased levels of autoantibodies against G-protein-coupled receptors. Many organic abnormalities found in ME/CFS correlate with symptom severity, indicating a relevant role in the disease process…In addition to ME/CFS itself, the lack of medical care and social support is particularly burdensome for those affected. In the health care system, patients with ME/CFS have to reckon with medical gaslighting and sometimes severe maltreatment – physicians convince patients…that they are psychosomatically ill. When admitted to hospital or rehabilitation programmes, patients with ME/CFS who are wrongly classified as having a psychosomatic illness are threatened with mistreatment, including activity-increasing therapies like GET that can seriously harm them".*

Professor Scheibenbogen emphasises the importance of educating physicians and the public about the incorrect and harmful psychosomatic model, as this misdiagnosis can lead to mistreatment, stigmatisation and difficulty in receiving appropriate care and benefits.

In one online group, Karen van Dyck wrote that Professor Sir Simon Wessely: *"Caused and continues to cause gross suffering and fear and sheer threat of being made worse by all NHS workers…Simon Wessely failed to put the Patient Voice above his own…he took away all knowledge that was there…he made an entire generation…of ME sufferers more ill. He is responsible for failure to listen and just being focused on his own career. That is not someone who has done society any good at all".*

This evidence – of which there is much more – confirms that Sir Simon's characterisation of ME patients contributes to the widespread clinical invalidation and resultant psychological harm so often experienced by people with ME.

Indeed, it is proven that physically sick people whose symptoms are dismissed by healthcare providers experience serious psychological harm, and that medical invalidation triggers a cascade of harmful consequences, leaving patients damaged and desperate (Allyson C Bontempo et al: Psychological Bulletin 2025: 151:4:399-427).

Mindful of the extent of published opposition to Professor Sir Simon Wessely's assertion that ME is but a "*false illness belief"*, might it be deemed to be purveying potential iatrogenic harm for Elsevier to purvey such disproven content as factual when it is not? Elsevier can hardly plead ignorance (and ignorance is no defence in law) because the internet is awash with scientific evidence that disproves their content about ME/CFS.

What Elsevier has published in the 11th edition of Kumar and Clark may be legally problematic on multiple counts:

- **Montgomery *v* Lanarkshire Health Board (2015)** – all clinicians are required by law to disclose material risks of treatment to intended recipients. The recommended interventions for ME/CFS in Elsevier's latest edition of Kumar and Clark fail to mention the legal requirement for warnings of the well-documented risks of GET-style interventions, thereby breaching the Montgomery standard

- **Misrepresentation and Negligence** – By presenting ME/CFS as MUS/FND (medically unexplained symptoms/functional neurological disorder, both of which carry a psychogenic label) Elsevier's latest edition of Kumar and Clark misrepresents a formally classified neurological disorder as psychiatric, potentially leading to inappropriate psychiatric interventions and avoidable harm, which could be a basis for medical negligence claims

- **Burden-shifting –** The authors state categorically in the textbook that "*recovery depends on positive patient engagement"*; this inverts responsibility, implying that non-recovery is due to the patient's failure to comply, rather than to ineffective or harmful interventions; this reflects denial of appropriate care.

By endorsing and actively promoting a discredited "treatment" paradigm and misclassifying the disease in question, Elsevier's published recommendations deviate from current clinical standards, propagate a model that is proven to be unsafe, and risk perpetuating institutional neglect for another generation – with foreseeable harm and legal liability.

Whilst Elsevier have a degree of legal protection over what they publish about ME/CFS (eg. through disclaimers and editorial policies), this protection does not allow for the publication of false or incorrect information, which can be challenged. In short, while publishers have legal protection, it is not absolute. Elsevier has responsibilities for maintaining the integrity of the published record. Their formal retraction policies show they can respond to credible challenges, especially those regarding patient health and ethical concerns.

Is it conceivable that what Elsevier has published about ME/CFS is legally challengeable?

In the meantime, as the House of Commons and the House of Lords have libraries in the Palace of Westminster, Elsevier's content about ME/CFS in the 11th edition of Kumar and Clark's "Clinical Medicine" will be brought to the librarians' attention and thus widely disseminated to Members of Parliament who, in turn, will be asked to raise it in Parliament and hence Elsevier's alleged misfeasance will be afforded increased publicity.