

Dear Elsevier,

Re: Updates for ME/CFS in next edition of Kumar and Clark's Clinical Medicine

We the undersigned, request that the next edition of Kumar and Clark's Clinical Medicine, due in 2025, addresses the following 5 points:

- 1) **That ME/CFS is taken out from Functional Somatic Syndromes and placed appropriately in the neurology section.**
- 2) **That the promotion of Graded Exercise and CBT is withdrawn as a treatment for ME/CFS,** due to NICE Guidelines 2021.
- 3) **That the PACE Trial is no longer promoted but withdrawn** because it promotes Graded Exercise and CBT as a cure: this goes against the recent NICE Guidelines.
- 4) **That the statement declaring no obvious pathology has been found, to be withdrawn.** Medical opinion believes that there is pathology of ME/CFS, e.g. Drs. Komaroff and Hyde, both specialists in ME/CFS have reported pathological findings in ME/CFS.ⁱ In addition, Elsevier published a scientific paper in July 2023 which declares pathology **has** been found in ME/CFS. *'The evidence presented in this review resonates with the notion that ME/CFS is characterized by physiological pathology, and not psychosomatic illness. This is a biologically-driven disease characterized by vascular (including haematological) pathology.'*ⁱⁱ
- 5) **That the derogatory character descriptions are removed, describing CFS/ME sufferers,** e.g. *'Outcomes are worse with...the conviction that the illness is entirely physical.'* (2020 edition, page 771.) Also, *'It is sometimes difficult to persuade a patient to accept what are inappropriately perceived as 'psychological therapies' for such a physically manifested condition.'*

In addition, that personality accusations against CFS/ME sufferers made throughout the chapter Functional somatic syndromes, are also removed e.g. *'avoidant behaviours; maladaptive illness beliefs,'* under perpetuating (maintaining) factors. (2020 edition, page 770.)

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In the latest edition of Kumar and Clark's Clinical Medicine 2020 (page 770), a sentence in the section 'Functional somatic syndromes' states that 'these functional disorders will be reclassified as their causes and pathophysiology are revealed.' The time for this reclassification has been long overdue for Myalgic Encephalomyelitis (ME), labelled as Chronic Fatigue Syndrome in the book.

Previous editions of Kumar and Clark's book have used CFS synonymously with ME (Myalgic Encephalomyelitis). The 2020 edition uses the term CFS without the term ME. However, as the most recent NICE Guidelines use both terms, we can ascertain that CFS in the 2020 book edition also refers to ME. (Reference: Myalgic

Encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management <https://www.nice.org.uk/guidance/ng206>)

Please consider the following facts:

Since 1969, the World Health Organisation has classified ME as a neurological illness (ICD 10 93.3).

The most recent NICE Guidelines demote CBT and state that GET must not be offered for CFS/ME patients.

Yet Kumar and Clark promote Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) for treatment of CFS under 'Rehabilitative Therapies', page 770. These therapies are promoted further under 'Management' and 'Prognosis'.

In October 2021, NICE Guidelines (NG 206) have written:

'It is not acceptable to recommend a programme of fixed incremental exercise, such as 'graded exercise' to an ME/CFS patient. Nor should any form of physical activity or exercise be presented as a cure: for example, as addressing imputed 'exercise avoidance' and/or physical deconditioning as a perpetuating factor in the patient's ill health. Programmes developed for people with other illnesses, or for healthy people, should not be offered to an ME/CFS patient. {1.11.14 and Box 4}

NG 206 continues to state that CBT should not be offered based on the assumption that people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS. CBT is not a cure for ME/CFS and should not be offered as such. [1.12.28; Box 5; 1.12.32; rationale, page 78]

Under Kumar & Clark's 'Prognosis', of Chronic Fatigue Syndrome, page 771, it mentions 'a large trial showed that about 60% improve with active rehabilitative treatments, such as graded exercise therapy and cognitive behavioural therapy...'. The trial referred to is presumably the PACE trial, as Kumar and Clark's 8th edition promotes PACE as further reading for CFS. The PACE trial has been shown to be flawed from the peer-reviewed publication by Tom Kindlon;ⁱⁱⁱ also by a paper written by academic David Tuller and several authors^{iv}.

In 2015, there were reported to be 9,000 peer reviewed articles on ME/CFS^v, studied by the U.S. National Institute of Health Pathways to Prevention and The Institute of Medicine. Both concluded through these 9,000 peer reviewed papers that ME/CFS is a serious physical disease, not psychological.

The description of ME/CFS in Kumar and Clark was publicly criticised in a government working group document, November 2006, entitled *Inquiry into the status of CFS/M.E. and research into causes and treatment*. MP Dr Ian Gibson specifically mentions the 5th and 6th editions of the Kumar and Clark Clinical Medicine books. In section 2.5 of this Inquiry, it states 'While CFS/M.E. remains only in the Psychological section of medical discourse, there can be little chance of progress.'^{vi}

We therefore urge Elsevier for changes reflecting our requests.

ⁱ https://www.hfme.org/Other/DefinitionBooklet_Sept_2011.pdf vascular pathology page 30

5b307e_b3a662c05f174937b9516d473a994c41.pdf (nightingale.ca) Limbic system of the brain is always injured in M.E. patients, page 15

[Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome \(omf.ngo\)](#) published JAMA July 5th 2019

ⁱⁱ [Cardiovascular and haematological pathology in myalgic encephalomyelitis/chronic fatigue syndrome \(ME/CFS\): A role for viruses - ScienceDirect](#)

ⁱⁱⁱ [\(PDF\) Reporting of harms associated with graded exercise therapy and cognitive behavioural therapy in myalgic encephalomyelitis/chronic fatigue syndrome | Tom Kindlon - Academia.edu](#)

^{iv} [Rethinking the treatment of chronic fatigue syndrome-a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT - PubMed \(nih.gov\)](#)

^v [The Significance to ME/CFS of the Landmark Change to the UK Law on Consent | Phoenix Rising ME/CFS Forums](#)

^{vi} [ME Inquiry Report Final Draft_A_\(erythos.com\)](#)