

Review of: "Management of Nutritional Failure in People with Severe ME/CFS: Review of the Case for Supplementing NICE Guideline NG206"

Susanne Bressan¹

¹ Technische Universität Berlin

Potential competing interests: No potential competing interests to declare.

From a patient's perspective, this is a much needed article on how to address the life-preserving needs of those severely affected by ME/CFS, i.e., providing adequate nutrition that is physiologically tolerated. I lack the medical expertise to assess all details of the medical evidence, but based on the science I have been reading and discussing in the patient community, I can follow all points raised by the author. So, I would mainly like to endorse the comments made by the first reviewer and suggest considering a small addition. In a current public inquest into the death of a patient with ME/CFS [1], reference was made to a Royal College guidance, stating that if the gut function is normal, Total Parenteral Nutrition (TPN) can only be given when the patient is detained under the Mental Health Act (MHA). The guideline referred to may be from the Royal College of Physicians [2]. If so, this is probably a misreading – only applying to patients that oppose receiving nutritional support, rather than patients with ME/CFS who *do* wish to be assisted with nutrition. Otherwise, patients with an apparent but unexplained physical inability to tolerate being fed through the gastrointestinal tract could find themselves in limbo, with no valid psychiatric reason for sectioning under the MHA but no agreed route to authorise TPN.

Given that such a gap in medical care can be fatal, I suggest including a short comment clarifying these recommendations.

References

[1] Hamilton, Fiona (2024), NHS staff thought patient's illness was self-inflicted, inquest told, The Times, 2024-07-24, <https://www.thetimes.com/uk/healthcare/article/nhs-staff-thought-patients-illness-was-self-inflicted-inquest-told-j2786lnm8>

[2] Royal College of Physicians. Supporting people who have eating and drinking difficulties. A guide to practical care and clinical assistance, particularly towards the end of life. Report of a working party. London: RCP, 2021. <https://shop.rcp.ac.uk/products/supporting-people-who-have-eating-and-drinking-difficulties>