

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

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Potential competing interests: I am a Physician and Rheumatologist who has offered private consultations for ME/CFS for the last 20 years.

This seems to me a thoughtful and reasoned review of how to approach the rare but important problem of malnutrition in the most severely affected cases of ME/CFS who are unable to feed themselves sufficiently to sustain a healthy weight.

Most GPs and physicians will come across this problem very rarely, perhaps once or twice in their careers. But to the individuals concerned and their families, it is a desperately serious problem which can and does result in the deaths of young people with ME/CFS due to malnutrition. Such cases are not the appropriate setting for a debate to occur over whether ME/CFS is an organic, psychological, or biopsychosocial problem, or some combination of any or all of them. Rather, the focus of healthcare professionals should be on effective, life-sustaining intervention. Edwards sensibly suggests that standard guidelines such as those of the British Association for Parenteral and Enteral Nutrition and the BACME (2024) resource document on the care of severe ME/CFS should be employed. These make it clear that there is a place for nasogastric or percutaneous endoscopic gastrostomy enteral feeding, and for parenteral nutrition in selected cases, and that a diagnosis of ME/CFS should not preclude such standard nutritional supportive measures alongside other supportive care.

From my experience in general hospitals in the UK, it seems that knowledge and understanding within the NHS of particularly the more severe forms of ME/CFS is not widespread. I think there is a need for better guidance, education, and training for all healthcare workers, and Prof Edwards' contribution is an important part of that effort.