BACME ME/CFS Tube Feeding Survey Report

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BACME media statement

The British Association of Clinicians in ME/CFS (BACME) has published a report summarising the findings of a UK-wide survey exploring experiences of tube feeding in people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The survey explored the perspectives of people with lived experience of ME/CFS, carers and healthcare professionals.

The report is intended to inform clinical practice and future guideline development. It does not advocate tube feeding as a treatment for ME/CFS. Rather, it recognises that, for a small number of people, tube feeding may become a necessary supportive intervention when severe nutritional compromise cannot be adequately managed by other means.

Tube feeding is likely to be needed by only a small proportion of people with ME/CFS. However, for those affected, nutritional compromise can be severe and potentially life-threatening, and the pathway to receiving appropriate care can be complex. The nature of ME/CFS can make the delivery of tube feeding challenging, and adjustments to standard practice may be needed. The survey highlights challenges experienced by patients, their families and clinicians, as well as examples of good practice.

The report identifies opportunities to improve care through earlier recognition of nutritional problems, timely access to dietetic assessment and specialist ME/CFS care, better multidisciplinary working, and improved education for healthcare professionals. It also highlights the need for ME/CFS-specific clinical guidance to support consistent, evidence-informed and individualised decision-making.

As there is currently very little published evidence in this area, the experiences shared through this survey provide valuable insights into an important but under-recognised aspect of ME/CFS care. BACME hopes the report will encourage collaboration between clinicians, researchers, patient organisations and people with lived experience to improve nutritional care, support the development of ME/CFS-specific guidance and stimulate further research.

BACME would like to thank everyone who contributed to the survey, particularly those living with severe and very severe ME/CFS, carers and healthcare professionals who shared their experiences, as well as those who gave their time to contribute to the development of the report.

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