

Severe ME Awareness Day 2023

Malnutrition in severe and very severe ME

Malnutrition can occur in people with severe and very severe ME for a number of reasons. In people with very severe ME one of the major causes is sheer debility; the person is just too debilitated to eat and drink sufficiently. Other causes include difficulty swallowing and gastrointestinal problems. A recent study on severe and very severe ME done in Norway found of those surveyed 37% had nausea and 50% had stomach pains when eating.

<https://www.mdpi.com/2077-0383/12/4/1487>

Published in 2021, *Life threatening Malnutrition in very Severe ME*, presented five case studies where people with very severe ME were allowed to develop life threatening malnutrition.

[Healthcare | Free Full-Text | Life-Threatening Malnutrition in Very Severe ME/CFS \(mdpi.com\)](https://www.mdpi.com/2077-0383/12/4/1487)

Despite being hospitalised due to the severity of their malnutrition there were delays in implementing tube feeding and clinicians only intervened when the malnutrition became life threatening.

Media coverage of people with ME needing tube feeding shows little seems to have changed since the publication of this paper and NICE Guideline 206 **Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management** which now includes a section on dietary management for people with ME and a separate section on dietary management for people with severe and very severe ME.

This is a more recent case study:-

A young adult with very severe ME, was admitted to hospital in 2023 malnourished and needing tube feeding. A nasogastric feeding tube was inserted as well as a peripherally inserted central catheter (PICC) line. However, hospital policy stated that she must be lying at 30 degrees to be fed through the nasogastric tube. She was not able to tolerate this, needing to lie flat at all times. The hospital was not willing to alter its policy to accommodate her needs or give Total Parenteral Nutrition via her PICC line. Her family were willing to take responsibility for her being fed lying flat, but the hospital wouldn't allow this. By this point she was struggling to take any calories orally and was only receiving IV saline. A concerned family member set up an online campaign which received over 15,000 signatures. Meanwhile, *The Times* newspaper also covered the story along with BBC News.

Following discussions by hospital clinicians and the media pressure the hospital decided to change its policy to allow the patient to be fed lying flat. Two family members were allowed to stay with her at all times in the side room she had been allocated and learnt to set up her tube feeds etc. Despite being in a side room and staff and doctors being supportive, the

hospital environment continued to exacerbate her ME so six weeks later she was fitted with a percutaneous endoscopic gastrostomy, (PEG) tube and discharged home on a combination of enteral and parenteral nutrition which her family administer at home.

This case is interesting in that pressure from family, social media and the national press along with sensible discussions by medical professionals brought about a change in policy at that hospital.

In the cases we hear about, struggling to have sufficient nutrition and hydration had been an ongoing concern for the patients and their families for some time before it developed into severe malnutrition.

People with severe ME who do not need tube feeding are nonetheless often at risk of developing malnutrition. We know people with severe ME often develop intolerances to certain foods or food groups. The additives and preservatives in ready meals often exacerbate their gastric problems causing diarrhoea leading to weight loss. A reduction in social care in the UK means often the time allocated by social workers for meal preparation has been significantly reduced often only allowing time for a ready meal to be heated. Typically, people with severe ME need meals cooked from scratch using fresh ingredients in order to prevent malnutrition. NICE Guideline 206 **Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management**

[Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#) does now recommend referring a person with severe ME to a dietician with a specialist interest in ME/CFS if they are at risk of malnutrition. However, guidance is in place for health and social care professionals to monitor and assess people at risk of malnutrition in the community including the Malnutrition Universal Screening Tool (MUST) which was developed by the Malnutrition Advisory Group.
https://www.bapen.org.uk/pdfs/must/must_full.pdf

It includes a guide to alternative measurements and 'subjective criteria' to assess whether a person is malnourished if they cannot be weighed. A Mid Upper Arm Circumference (MUAC) measurement can be used to calculate an estimated BMI. Subjective criteria includes whether the person looks underweight, whether clothes have become looser, daily oral intake and reduced oral intake, appetite and swallowing problems over the previous 3-6 months. Using an objective criterion, i.e., calculating a BMI, or subjective criteria a nutritional risk score is given from low to high risk. A score of high risk necessitates a referral to a dietician or specialist nutrition team. This tool should enable professionals to identify those at risk of malnutrition early and respond accordingly thereby avoiding people becoming malnourished.

Likewise, if a person with very severe ME does find themselves needing to be admitted to hospital suffering from malnutrition not only can health care professionals refer to NICE Guideline 206 which states that people with severe and very severe ME may need tube feeding but they **should** also be referring to NICE Clinical Guideline 32, *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition*
<https://www.nice.org.uk/guidance/cg32>

It gives specific guidance around implementation of tube feeding enterally, i.e. via a nasogastric tube, relating to weight, percentage of weight loss, oral intake etc and states that if enterally feeding is inadequate then parenteral feeding should be considered. Furthermore, it says a combination of oral, enteral and parenteral nutrition can be used for a patient who is malnourished.

Evidence has shown early intervention tube feeding in very severe ME to be beneficial as it conserves energy [Healthcare | Free Full-Text | Severe ME in Children \(mdpi.com\)](#) and stops the malnutrition becoming so severe. Medical education in both ME and nutrition has historically been poor. Hopefully this will improve with medical education being taught to all final year medical students starting in the academic year 2023-4. See piece on Medical Education Campaign [on page13](#) .

Currently, allied health care professionals are often unaware that severe ME/CFS can cause nutritional difficulties; ME needs to be recognised as a risk disease for malnutrition. An early warning system needs to be put in place so that when a patient or their carer report difficulties maintaining nutrition and hydration needs prompt action is taken. The inclusion of ME in nutritional guidelines at a national level would help bring about recognition of the condition. However, it is imperative that health care professionals use the tools and guidelines that were specifically designed to manage and treatment malnutrition in conjunction with NICE Guideline 206.

With this in mind, 25% ME Group has selected the relevant sections from NICE Guideline 206 and NICE Clinical Guideline 32 as well as the links for other useful websites for your ease of use. You can find these on [the following 2 pages](#).

Guidelines on Nutrition for ME Patients

The NICE Clinical Guideline NG206 for ME/CFS: diagnosis and management includes a section on dietary management for people with ME/CFS and a separate section specifically for people with severe or very severe ME.

Dietary management and strategies in Section 1.12 Symptom management for people with ME/CFS, states:

1.12.19 Emphasise to people with ME/CFS the importance of adequate fluid intake and a well-balanced diet according to the NHS eat well guide.

1.12.20 Work with the person and their family or carers (as appropriate) to find ways of minimising complications caused by gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing and eating food.

1.12.21 Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often. Explain that not eating or drinking may increase their nausea.

1.12.22 Refer people with ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS if they are:

losing weight and at risk of malnutrition

gaining weight

following a restrictive diet.

1.12.23 Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those

who are housebound or bedbound. For advice on vitamin D supplementation, see the NICE guideline on vitamin D.

1.12.24 Explain to people with ME/CFS that there is not enough evidence to support routinely taking vitamin and mineral supplements as a cure for ME/CFS or for managing symptoms. If they choose to take a vitamin or supplement, explain the potential side effects of taking doses of vitamins and minerals above the recommended daily amount.

1.12.25 Refer children and young people with ME/CFS who are losing weight or have faltering growth or dietary restrictions to a paediatric dietitian with a special interest in ME/CFS.

1.12.26 For advice on food allergies in children, see the NICE guideline on food allergy in under 19s.

Dietary management and strategies in Section 1.17 Care for people with severe or very severe ME/CFS states:

1.17.10 Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian with a special interest in ME/CFS.

1.17.11 Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of:

- restrictive diets
- poor appetite, for example linked with altered taste, smell and texture
- food intolerances
- nausea
- difficulty swallowing and chewing.

Follow the recommendations on screening for malnutrition and indications for nutrition support, in the NICE guideline on nutrition support for adults.

1.17.12 Give advice to support people with severe or very severe ME/CFS, which could include:

- eating little and often
- having nourishing drinks and snacks, including food fortification
- finding easier ways of eating to conserve energy, such as food with softer textures
- using modified eating aids, particularly if someone has difficulty chewing or swallowing
- oral nutrition support and enteral feeding.

The NICE Clinical Guideline CG32, Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition covers adults who are malnourished in hospital or their own home or a care home.

Section 1.2 Screening for malnutrition and the risk of malnutrition in hospital and the community states:

1.2.1 Screening for malnutrition and the risk of malnutrition should be carried out by healthcare professionals with appropriate skills and training.

1.2.6 Screening should assess body mass index (BMI) and percentage unintentional weight loss and should also consider the time over which nutrient intake has been unintentionally reduced and/or the likelihood of future impaired nutrient intake. The Malnutrition Universal Screening Tool (MUST), for example, may be used to do this.

Section 1.3 Indications for nutrition support in hospital and the community states:

1.3.1 Nutrition support should be considered in people who are malnourished, as defined by any of the following:

a BMI of less than 18.5 kg/m²

unintentional weight loss greater than 10% within the last 3 to 6 months

a BMI of less than 20 kg/m² and unintentional weight loss greater than 5% within the last 3 to 6 months.

1.3.2 Nutrition support should be considered in people at risk of malnutrition who, as defined by any of the following:

have eaten little or nothing for more than 5 days and/or are likely to eat little or nothing for the next 5 days or longer

have a poor absorptive capacity, and/or have high nutrient losses and/or have increased nutritional needs from causes such as catabolism.

1.3.3 Healthcare professionals should consider using oral, enteral or parenteral nutrition support, alone or in combination, for people who are either malnourished or at risk of malnutrition, as defined in recommendations 1.3.1 and 1.3.2. Potential swallowing problems should be taken into account.

1.3.5 Healthcare professionals should ensure that people having nutrition support, and their carers, are kept fully informed about their treatment. They should also have access to appropriate information and be given the opportunity to discuss diagnosis and treatment options.

Section 1.7 Enteral tube feeding in hospital and the community states:

1.7.1 Healthcare professionals should consider enteral tube feeding in people who are malnourished or at risk of malnutrition, as defined in recommendations 1.3.1 and 1.3.2, respectively, and have:

inadequate or unsafe oral intake and
a functional, accessible gastrointestinal tract.

1.7.7 People who meet the criteria in recommendation 1.7.1, with upper gastrointestinal dysfunction (or an inaccessible upper gastrointestinal tract) should be considered for post-pyloric (duodenal or jejunal) feeding.

1.7.8 Gastrostomy feeding should be considered in people likely to need long-term (4 weeks or more) enteral tube feeding.

1.7.9 Percutaneous endoscopic gastrostomy (PEG) tubes that have been placed without apparent complications can be used for enteral tube feeding 4 hours after insertion.

1.7.11 For people being fed into the stomach, bolus or continuous methods should be considered, taking into account patient preference, convenience and drug administration.

1.8 Parenteral nutrition in hospital and the community states:

1.8.1 Healthcare professionals should consider parenteral nutrition in people who are malnourished or at risk of malnutrition as defined in recommendations 1.3.1 and 1.3.2, respectively, and meet either of the following criteria:

inadequate or unsafe oral and/or enteral nutritional intake
a non-functional, inaccessible or perforated (leaking) gastrointestinal tract.

NICE Nutritional Support in Adults Quality Standard (QS24)

This covers care for adults who are malnourished or at risk of malnutrition in hospital or in the community. It includes identifying people at risk of malnutrition and providing nutrition support, including dietary changes and artificial nutrition support

Overview states:

The quality standard for nutrition support in adults requires that all care services take responsibility for the identification of people at risk of malnutrition and provide nutrition support for everyone who needs it. An integrated approach to the provision of services is fundamental to the delivery of high-quality care to adults who need nutrition support.

Other useful resources:-

British Association of Parenteral and Enteral Nutrition (BAPEN) <https://www.bapen.org.uk/>

PINNT- a patient led charity which supports for people who are being tube fed
<https://pinnt.com/Home.aspx>

The Malnutrition Universal Screening Tool

https://www.bapen.org.uk/pdfs/must/must_full.pdf

