Severe ME Awareness Day 2023

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.

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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/m^2
- unintentional weight loss greater than 10% within the last 3 to 6 months
- a BMI of less than 20 kg/m^2 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