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LIFE-THREATENING MALNUTRITION IN VERY SEVERE MYALGIC ENCEPHALOMYLITIS/CHRONIC FATIGUE SYNDROME (ME/CFS)

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Patients with very severe Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) can experience difficulty maintaining their nutrition and hydration. In the most severe cases it is not uncommon. The commonest reason is simple debility. Dysphagia, severe gastrointestinal problems in tolerating food, possibly indicative of Mast Cell Activation Disorder, and conditions such as gastroparesis may also be contributing factors. These patients require enteral or parenteral nutrition. In our experience there is often a delay in implementing Clinically Assisted Nutrition and Hydration (CANH), until the malnutrition becomes life-threatening. Clinicians are often unaware severe ME/CFS can present with this problem, and have a tendency to view the symptoms as purely psychological. Of the literature found, only brief reference is made to the issue in the 2021 NICE Guidelines [1] and the 2004 Paediatric Guidelines [2] from the Royal College of Paediatrics and Child Health. Staff and volunteers at a UK based charity supporting people with severe and very severe ME/CFS had become aware of the problems accessing CANH.

The charity created a questionnaire for members who had experience of being enterally or parenterally fed. In summer 2019 an invitation was placed in the charity’s newsletter inviting members meeting the criteria to complete the questionnaire. From the responses, five anonymized case reports, were written.

Despite very low Body Mass Indexes and high Malnutrition Universal Screening Tool (MUST) scores, when admitted to hospital, all five cases suffered significant delays in nutritional intervention. Clinicians only intervened, when the malnutrition and dehydration became life-threatening. The primary clinical need was neglected in favour of psychiatric intervention and all of the five cases were deemed, incorrectly, to be suffering from Anorexia Nervosa. Their dysphagia was also felt to be a psychological manifestation. The clinicians involved appeared unaware that severe ME/CFS can lead to difficulties maintaining nutrition and fluid requirements. Failure to recognise this resulted in clinical inertia and put the patients at risk of diseases related to malnutrition, and of refeeding syndrome [3] when intervention finally occurred.

Alongside NICE Guideline 206 which states the possible need for tube feeding in patients with ME/CFS, all the patients met the criteria for tube feeding as set out in NICE Guideline 32 [4]. Reluctance to tube feed can occur because of the concern that the patient will become dependent on it. However, the case reports show this was not the case. Patients with ME/CFS require domiciliary medical care. Positive improvements occurred in all cases with the involvement of a Home Enteral Nutrition Service (HENS). Concerns have been raised around the safety of siting Nasogastric tubes (NGTs). However, a large study has shown that with the correct protocols in place appropriately trained nurses can accurately site NGTs in the community [5].

Clinical practice in the care of patients with severe ME/CFS needs to be improved and a guideline with an early warning system put in place for prompt escalation to tube feeding as soon as a patient develops nutritional difficulties. The inclusion of severe ME/CFS in national nutritional guidelines would bring about recognition of the condition, helping to ensure a proactive approach be adopted.

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GOING DIGITAL IN A PANDEMIC: TRANSFORMING DIETETIC SERVICES BY THE USE OF DIGITAL PLATFORMS TO DELIVER SAFE AND SUSTAINABLE CARE DURING COVID-19 AND BEYOND

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In April 2020, with the realisation that dietetic practice had to change when covering critical care units, a group of specialist dietitians led the development of a hand held digital dietetic record that could be safely used within the critical care unit avoiding the use of paper and it being transferred off the COVID critical care unit. Being digital enabled remote working, decreased footfall and increased safety for patients and staff. This was the first step in a journey that saw the transformation from a paper based system to one that is entirely digital across all dietetic areas within inpatient and outpatient settings and in both adults and paediatrics by the end of 2020.

Together with the introduction of video patient consultations, video conferencing applications and electronic prescribing, our approach to provide dietetic intervention has changed dramatically. It has enabled a dietetic service to embrace remote working which has been helpful during periods of self-isolation e.g. virtual; ward rounds, group sessions, 1:1 education, interviews, training and development.

Collaborative working included the newly developed “digital dietetic group” and the “H Digital” trust group and DXC technologies to develop a clinical data capture (CDC) form. The clinical basis followed the layout as advised in the Model and Process for Nutrition and Dietetic Practice to ensure that data capture was relevant and followed a standard process. The purpose of the Model and Process is to describe, through six steps, the consistent process dietitians follow in any dietetic intervention. It articulates the specific skills, knowledge and critical reasoning that dietitians deploy, and the environmental factors that influence the practice of...
dietetics. This does not take away dietitians’ autonomy. Instead, it enables a consistent approach to dietetic care, with the service user at the centre. This completed form was available as a complete ‘dietetic’ digital record. A key objective within the Organisation’s Digital Strategy and it will reduce risks by enhancing clinical effectiveness and patient safety. The wider multi-professional team found dietetic digital records invaluable, to be able to access 24/7 allowing for continuity of care when unable to speak directly to the dietetic team this included alternative feeding regimens and clinical reasoning that subsequently influenced treatment decisions and allowed for patient care out of hours. This led onto working with trust digital team on electronic prescriptions for oral nutritional support and enteral feeds, digital patient lists (for caseloads), digital design of food and fluid charts for the organisation. The enhancement in clinical safety and patient care where is it required has been phenomenal and an exciting journey we are keen to share. The design will enable dietetic outcomes to be collected directly from digital record.

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PATIENTS’ EXPERIENCE OF A NUTRITION MDT CLINIC

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The nutrition multi-disciplinary (MDT) clinic at a district general hospital (DGH) runs monthly and includes a gastroenterology consultant, dietitian and nutrition nurse specialist. Patients that are seen typically have complex nutritional problems including gastroparesis and short bowel syndrome and require review by multiple members of the MDT. 29 Patients attended the Nutrition MDT Clinic between April 2019 and March 2021. 3 of these have since passed away. 9 of these patients have been discharged from our care and 4 patients have only been seen once and therefore were deemed inappropriate to take part in the survey. 13 patients were contacted by telephone to take part in a questionnaire to evaluate the effectiveness of the nutrition MDT clinic. 12 of these agreed to take part. 1 was unable to be contacted so could not be involved.

Nine statements were given by the above participants, who had to respond with strongly agree, agree, neither agree nor disagree, disagree or strongly disagree to the following statements:

1. The Nutrition MDT clinic is better than a normal outpatient clinic
2. The Nutrition MDT clinic is helpful to me
3. I feel listened to in the Nutrition MDT clinic
4. I feel the Nutrition MDT are knowledgeable
5. I feel my symptoms have improved since being under the care of the Nutrition MDT
6. I feel able to ask questions in clinic
7. I have the time to address all my issues in clinic
8. I feel able to contact the Nutrition Team outside of the Clinic room
9. I find it easy to contact the Nutrition Team when I am at home
10. (83%) patients strongly agreed and 2 (17%) agreed that the Nutrition MDT clinic is better than a normal outpatient clinic and that the Nutrition MDT clinic is helpful to them. 11 (92%) participants strongly agreed and 1 (8%) participant agreed that they feel listened to in the Nutrition MDT clinic and feel that the Nutrition MDT is knowledgeable. 7 (58%) patients strongly agreed and 5 (42%) patients agreed that their symptoms have improved since being under the care of the Nutrition MDT. All patients agreed that they feel able to ask questions in clinic, that they have the time to address all their issues in clinic, that they feel able to contact the Nutrition Team outside of the clinic room and that they find it easy to contact the Nutrition Team when they are at home.

Patients clearly benefit significantly from an MDT approach in relation to their nutrition, with involvement from a consultant gastroenterologist, dietitian and nutrition specialist nurse. Having 3 professionals in one clinic streamlines the approach to patient care and provides patients with a breadth of clinical expertise producing clear multifaceted plans, with clear lines of communication outside of the clinic room with the use of nutrition nurse helpline that is always responded to promptly.

THE NUTRITIONAL MANAGEMENT OF PEOPLE LIVING WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS): A CROSS-SECTIONAL SURVEY OF UK DIETITIANS

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People living with Amyotrophic Lateral Sclerosis (pwALS) face many challenges to taking adequate nutrition and hydration (1). Reduced dietary intake, combined with raised resting energy expenditure (REE) (2), contribute to the high prevalence of malnutrition in ALS (3), with low BMI and weight loss being independent prognostic indicators of survival (4). There is a lack of evidence focusing on the nutritional management of people living with ALS.

This study reports the responses of UK dietitians to a survey exploring the nutritional management of pwALS. The survey was distributed online using snowball sampling technique between September and November 2018. Of the 130 dietitians responding to the survey, 87% were currently providing dietetic care to pwALS. Dietitians most frequently reported (66%) that pwALS formed 20% of their total patient caseload. Less than half (42%) of dietitians reported that nutritional screening took place in their organisation and 44% reported referrals were made too late. With regards nutritional assessment, the majority (83%) used predictive equations for resting energy expenditure (REE) not validated in ALS. Most dietitians (91%) reported that they would set a weight gain goal for pwALS with a BMI under 18.5kg/m². However, only 28% reported that they would set a weight gain goal for those with a BMI between 18.5 and 25.0, and none would do so for those with a BMI greater than 25kg/m², instead recommending weight maintenance or even weight loss. Only 23% of dietitians reported that the ‘food first’ approach was effective in ALS. Most dietitians (43%) reported that pwALS were not weighed frequently enough. The reported lack of nutritional screening and late referral for dietetic input may result in the risk factors associated with malnutrition in ALS not being identified in a timely way.

Reliance on estimates of REE not validated for pwALS and setting conservative weight goals may not be in line with the current evidence base. Further research is required to better understand the optimal nutritional management in ALS and the development of nutritional interventions to improve outcomes for pwALS.

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