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DYSPHAGIA AND MOTOR NEURONE DISEASE: A CASE STUDY

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Motor neurone disease (MND), or Amyotrophic lateral sclerosis (ALS), refers to a group of related disorders caused by the degeneration of the motor neurones in the brain and spinal cord.[1,2] It affects up to 5,000 people in the UK at any one time.[3] The symptoms of MND can be widespread with motor neurone degeneration causing weakness and wasting of muscles which can affect mobility, speech, swallow and respiratory function.[4,5]

Victoria has worked as a Dietitian for over 10 years and has worked in both acute and clinical community settings. She is currently specialising in Stroke and Diabetes.

There is currently no cure for MND, so care is focused on symptom management and palliation[4] in order to maintain quality of life. A multidisciplinary approach is essential, as care of patients with MND is complex and relies on expertise from different disciplines to undertake assessment and co-ordinate appropriate care and treatment.[5,8,2]

Dysphagia associated with bulbar muscle involvement is common in MND[5] and is present in 45% of patients at diagnosis, with 81% of all MND patients experiencing dysphagia irrespective of onset.[2,6,8] It can affect all stages of swallowing due to weakness developing in the muscles involved, including the tongue, lips, facial muscles, pharynx and larynx[7,8] (see Table 1). Swallowing disorders resulting in dysphagia are by far the most important cause of nutritional impairment.[8]

Table 1: Stages of swallowing[8,9]

Stage of swallow	Characteristics in MND
Preparatory stage	• Difficulty getting food/liquid into the mouth • Weak movement of lips, tongue & jaw affecting ingestion and bolus swallowing • Leakage of fluid on drinking due to poor lip seal
Oral stage	• Weak movement of lips, tongue and jaw • Poor mastication • Difficulty in forming a food bolus • Poor bolus manipulation • Weak bolus propulsion • Difficulty swallowing saliva
Pharyngeal stage	• Delay initiating pharyngeal swallow • Pharynx residue post swallow • Decreased laryngeal elevation • Aspiration before, during and after swallow

Table 2: Weight and BMI

Consultations	Weight (kg)	BMI (kg/m²)
1	76	24.3
2	73.6	23.6
3	70.2	22.5
4	66.8	21.4
5	68.2	20.4
6	65	20.8
7	63.5	20.3

CASE STUDY: 66-YEAR-OLD MALE DIAGNOSED WITH MND

Here I detail the nutritional management of a 66-year-old gentleman named Jim, who was assessed by a dietitian two months following diagnosis of MND. He was referred from the multidisciplinary MND team meeting.

Prior to initial assessment, I liaised with the Speech and Language Therapy (SLT) team to obtain details on recent swallow and communication assessments. At this point, he had no reported swallowing issues and was safe with normal diet and fluids. His main issues at this time was dysarthria.

1 Assessment

Usual weight was reported to be 76kg which had remained stable for a number of years and body mass index (BMI) was within a normal range (Table 1, point 1). He was retired from employment, although he continued to maintain an active life through a house renovation project and was often working up to eight hours per day. He had no previous medical history and had recently been prescribed the medication Riluzole which can help to slow neurone damage.

Dietary intake was varied, balanced and sufficient to meet his estimated nutritional intake at this time. No concerns were reported with fluid intake which appeared to meet his requirements. No issues were reported with coughing or choking on foods.

The short-term dietetic aim was to maintain his current weight and nutritional status. Dietetic advice included a food-first approach with emphasis on the importance of maintaining dietary intake from energy dense meals, snacks and fluids.

2 Identification of nutrition and dietetic diagnosis

As Jim had the bulbar form of MND knowledge of this led me to think about longer-term implications of dysphagia and how this would impact on his nutritional status. I therefore enquired regarding his knowledge of the condition and how much information they would like to receive. Although they had received some information from the neurologist and accessed the Motor Neurone Disease Association website, they wanted to know more about dysphagia and management options for the future. An explanation of this was provided in addition to looking into future options for nutritional support including gastrostomy placement.

Although I acknowledge that these are quite difficult conversations to have with patients and their relatives, it is important to address these issues and options early to ensure that individuals can have time to make an informed choice. The importance of discussing nutritional management options issues early is widely documented,[1-10] however, I acknowledge that this approach may not be suitable for all patients who may be struggling to come to terms with their condition and decisions involved in planning for the future.[10]

Jim was reviewed three months later; weight had decreased by 2.4kg (3.2%) (Table 2, point 2) and I had received information from SLT outlining their current recommendations of level E diet and stage 1 thickened fluids from a recent swallow assessment.[11] Dietetic assessment revealed that he was still eating and drinking well and appeared to be meeting dietary and fluid requirements despite advised changes to the texture of diet and fluids. No changes had been made to his activity levels and he continued to work for eight hours a day on his house.

NUTILIS PRE-THICKENED: SUPPLEMENTS FOR PEOPLE WITH DYSPHAGIA

- A range of pre-thickened ONS that are nutritionally complete[†], high in energy and contain protein — to help fill the nutritional gap
- Easier, more reliable & safer than thickening standard ONS[1]
- 10p cheaper per unit than the competitor product*

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*MIMS July 2016 compared to Fresubin® Thickened Stage 1 and 2.
[†] RNI for males 19-50 years (excluding Na, K, Cl, Mg).

Reference: 1. Schulz R-J et al. Clin Nutr Suppl, 2010; 5(2): 212.

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3 Plan nutrition and dietetic intervention

The short-term dietetic advice focused on appropriate food and fluid textures, in addition to reiterating methods of food fortification. Weight loss at the time was thought to be due to his daily activity and/or muscle wastage; however, subsequent literature has shown that 60% of patients with MND show a 10% increase of resting energy expenditure.[8]

The use of nutritional products was suggested to maximise energy and protein intake and Fresubin thickened stage 1 twice daily was initiated to provide an additional 600kcal and 40g protein per day with a short-term aim to arrest weight loss.

Jim and his wife had spent time thinking about our previous conversation and wanted to know more about the longer-term option of gastrostomy placement. A meeting was, therefore, set up with a Clinical Nutrition Nurse Specialist (CNNS).

Four weeks later, a joint consultation with a CNNS took place. Nutritional assessment revealed further weight loss (Table 2, point 3) and Jim had started to visibly notice the loss of muscle mass on his arms. He reported reduced strength and fatigue and had decreased work time to two hours per day. Difficulties with maintaining nutritional intake were reported, with Jim becoming tired in the evening causing him to take longer to complete his evening meal. He remained on a level E diet and stage 1 thickened fluid and was continuing to take oral nutritional supplements twice daily. Speech was becoming slow and labored and he was experiencing excessive salivation for which his GP had prescribed a hyoscine patch.

The short-term goal was to prevent further weight loss and strategies were suggested to enhance his intake when feeling less lethargic; this included changing his meal structure by having his larger meal earlier in the day and smaller meal in the evening. Dessert based nutritional products were trialed, but he wished to continue with Fresubin thickened stage 1 with an increase to 3 x 200ml daily (900kcal, 60g protein).

The CNNS discussed percutaneous endoscopic gastrostomy (PEG) tube and outlined the indications, procedure and possible complications. The risks versus benefits of the procedure were discussed[12] and the implications of delaying the decision of PEG placement if respiratory function was to deteriorate, which is common in MND. Additionally, the options of continuing with oral intake versus gastrostomy were discussed alongside specific issues such as chest infections, reduced mobility and who would be responsible for the care of the tube. Jim expressed that he wanted to proceed with PEG placement and a planned admission was arranged.

Unfortunately, one week before the planned admission for PEG placement, Jim had an emergency admission to hospital with a myocardial infarction and respiratory issues. He was commenced on non-invasive ventilation (NIV). SLT carried out a swallow assessment on the ward and found that swallow had deteriorated markedly and advised a period of Nil by Mouth (NBM).

4 Implement nutrition and dietetic intervention

To provide nutrition, consent was obtained to place a Nasogastric tube (NGT) and a 15-hour continuous feeding regime commenced. PEG placement was cancelled due to increased risks. However, after a two-week admission, Jim was deemed safe to go home with his NGT in place. In preparation for this, the feeding regime was changed from a continuous method to bolus regime to fit in with his daily life and a nasal bridle was placed to reduce the risk of NGT displacement. Training was delivered by a CNNS to ensure that Jim and his wife were competent in administering feed and medications and a timetable was devised with the assistance of a pharmacist.

Prior to discharge, SLT had reviewed Jim's swallowing and advised oral trials of 3 x 1/2 teaspoons of stage 2 thickened fluids no more than half hourly for comfort rather than rehabilitation of swallow. As this was insufficient to meet his nutritional requirements, full requirements were to be met via his NGT.

Speech had significantly deteriorated during his admission and SLT had provided an iPad to help with communication; however, he preferred the use of a pen and paper to express his needs.

Dysphagia is common amongst patients with MND . . . long-term methods of nutritional management need to be considered and discussed with patients, relatives and carers . . .

5 Monitor and review

A domiciliary visit was carried out four weeks following discharge to review and assess nutritional status. Weight had continued to decrease (Table 2 point 4). Jim and his wife were administering 4 x 200ml bolus feeds per day which was providing approximately 1,600kcal, 68g protein and 2,000ml of fluid. No concerns were expressed with the management of administering bolus feeds and medications and this should have been sufficient to meet his current needs. During this period, there was no change to oral intake which remained as per SLT advice. He reported enjoying his oral trials for comfort and was taking Fresubin thickened stage 2 and thickened coffee. It was suggested that in view of weight loss, bolus feeds were to be increased to 5 x 200ml daily, providing 2,000kcal, 85g protein, 22,00ml fluid daily.

Following his recent hospital admission, the CNNS had liaised with members of the Nutrition Support team who arranged a planned admission for a radiologically inserted gastrostomy (RIG). This was deemed a more suitable option than PEG at this point due to recent respiratory issues and the need for NIV.

The RIG was placed with no issues and Jim resumed his usual bolus feeding regime. He felt his quality of life had improved and he no longer had the irritation from the NGT and no pressure of meeting his nutritional requirements orally. One month post-RIG placement, weight had increased (table 2, point 5) although swallow function dysphagia had deteriorated and he has been advised to remain nil by mouth due to frequent chest infections. He communicated that he was content with this as he had started to lose confidence with taking oral trials.

6 Evaluation

In subsequent visits, no concerns were expressed regarding his bolus feeds or nutritional management, although Jim's wife took over administering feeds when he started to lose strength in his hands. Weight decreased (Table 2, points 6 and 7) and symptoms of MND continued to progress rapidly post RIG placement and, unfortunately, he passed away eight months later.

Dysphagia is common amongst patients with MND and although short-term methods of nutritional support can be put into place to prevent deterioration in nutritional status, long-term methods of nutritional management need to be considered and discussed with patients, relatives and carers at a timely point to ensure nutritional status does not deteriorate.

For dietitians, it sometimes can be uncomfortable initiating conversations, but, irrespective of the decision made, early discussions allows individuals to make evidence-based informed choices.

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Questions relating to: ***Dysphagia and motor neurone disease: a case study***
Type your answers below, download and save or print for your records, or print and complete by hand.

Q.1	Explain motor neurone disease (MND) and its symptoms.
A	
Q.2	What does the nutritional management of MND focus on?
A	
Q.3	Why is dysphagia common in MND?
A	
Q.4	Explain the three stages of swallow.
A	
Q.5	Describe the short-term dietetic advice that can be given to a patient with MND.
A	
Q.6	What dietetic strategy can be suggested to enhance intake for weight loss?
A	
Q.7	Outline the nutritional management of the patient in the case study during domiciliary visits.
A	
Q.8	Explain why a radiologically inserted gastrostomy (RIG) was considered a suitable option for the case study patient.
A	

Please type additional notes here . . .