Case 1

Tube feeding in progressive neuromuscular disease

Clinical summary

Presentation/clinical history

Mr H, 57 years, physical activity teacher

- Diagnosed with motor neurone disease/amyotrophic lateral sclerosis. Life expectancy likely to be ≤ 3 years. Under investigation 12 months prior to diagnosis – initially presented with stroke/TIA symptoms.
- Dysphagia reported and has had 2 recent chest infections. Assessed by speech and language therapist – risk of aspiration reported. Commenced thick pureed diet and stage 2 (mildly thick) fluids.
- Mr H using lightwriter to communicate due to dysarthria.
- Dietetic review at home to discuss feeding options in the longer term, referred to gastroenterologist.[4] Commenced Fresubin thickened ONS 1-2 x daily as able. Also provided with food fortification advice.
- Medical history: mild hypertension
- Medications: riluzole, hyoscine butylbromide patches, paracetamol
- Biochemistry: Na 141 mmol/l, K 4.4 mmol/l, Ur 6.0 mmol/l, Cr 72 µmol/l, Ca 2.25 mmol/l, PO_4 1.08 mmol/l, Mg 0.82 mmol/l

Early enteral nutrition plays an important role meeting nutritional needs in patients with neurological diseases and subsequent dysphagia.[4]

Weight history

Normal weight	86 kg (BMI: 27.5 kg/m²)
At diagnosis	78 kg (BMI: 24.9 kg/m²)
Current weight	75.3 kg (BMI: 24.0 kg/m²)

- Weight loss: **9.3%** before diagnosis – gradual loss continues (total approx. **12.4%** from onset of symptoms)

Nutritional assessment

Estimated nutritional requirements

- Energy: 2823 kcal[5,6] (25 kcal x 75.3 kg + 1.5 physical activity factor due to reduced mobility)
- Protein: 75.3-113 g (1-1.5 g/kg)[7]
- Fluid: 2330 ml (using the 100/50/15 formula)[8]

Note: Mr H's energy requirements may be increased due to motor neurone disease, therefore need to use estimate requirements as a baseline. However, need to monitor as likely to gain fat mass and not lean body mass with any excess calories and protein.[9-11]

Dietetic assessment

- Reviewed by community dietitian. Discussed feeding options including bolus, intermittent and continuous feeding.
- Oral intake important to help maintain swallow for as long as possible, as well as for quality of life purposes.
- Weight has been falling gradually but as swallowing now deteriorating, nutritional status likely to fall further.
- Intake approx. 800 kcal, 15 g protein and 1200 ml fluid (including ONS) – deficit of approx. 2000 kcal, 60–98 g protein and approx. 1300 ml fluid.

Aim

- Meet nutritional requirements and maintain nutritional status as long as possible due to progressive nature of disease. Ensure Mr H is able to meet hydration requirements despite dysphagia.

Tube feeding with Fresubin

Nutrition therapy

- 15Fr Freka PEG tube sited successfully. Feed to commence 3 hours post PEG insertion.[12]
- Meeting Mr H's protein requirements may help maintain muscle mass and prevent catabolism.
- Fibre feed beneficial to maintain gut physiology.[13,14]
- A range of container options is beneficial as feed likely to increase over time.
- Home training arranged prior to discharge with patient and family.

Fresubin 2 kcal HP Fibre contains 20µg of vitamin D in the RDD which may improve muscle strength and muscle function and may help reduce the risk of fractures and falls as mobility likely to decrease as disease progresses.[15-18]

Day

Feeding regime

1. (3 hours post PEG insertion) Fresubin 2 kcal HP Fibre 500 ml at 25 ml/hr for approx. 7 hrs (4 p.m.–11 p.m.) (using 175 ml feed).
2. (At home) Fresubin 2 kcal HP Fibre 1000 ml at 50 ml/hr x 14 hr (approx. 7 a.m.–9 p.m.) (using 700 ml of feed).
3. (At home) Fresubin 2 kcal HP Fibre 1000 ml at 75 ml/hr x 13.5 hr.

100 ml water flushes pre- and post-feed to maintain hydration status recommended. Also not going to take all medications via tube therefore advised to take 100 ml pre- and post-feed (at present 4 x daily as regular analgesia commenced).

Feed providing 2000 kcal, 100 g protein, 15 g fibre and 1710 ml fluid. Reinforced need to maintain 30-degree angle during feeding and for 30 min. afterwards.

Week

Monitoring/follow-up

1. Reviewed Mr H at home and feeling a bit better than previously. Now well hydrated. No problems with feed tolerance, running at 75 ml/hr x 10 hr. Oral intake as per previous assessment and consuming 1 x Fresubin thickened ONS daily. Stoma site slightly red – encouraged to clean and rotate daily. Bowels moving every 2 days – normal for him, urine output good. Weight ↓1.3 kg to 74 kg due to being nil by mouth and not meeting full nutritional requirements prior to tube insertion. Increase feeding to 100 ml/hr x 10 hr Fresubin 2 kcal HP Fibre. Review in 1 week.
2. Happy with current regime. Tolerating Fresubin 2 kcal HP fibre 1000 ml at 100 ml/hr x 10 hr. Weight is stable to 74.2 kg therefore meeting nutritional requirements. Stoma site looks healthy and no problems reported with bowels or urine output. Increased rate of feed to 125 ml/hr x 8 hrs (aim to reduce feeding time to allow activities during the day).
3. No new problems with feeding – swallowing has not deteriorated significantly but Mr H is well aware of progressive nature of disease. No chest infections since PEG tube insertion. Continue with feed overnight on Fresubin 2 kcal HP Fibre 1000 ml at 150 ml/hr x 6.5 hrs in the evening with 100 ml water flushes pre- and post-feed and -medication. Review monthly.

Early enteral feeding in patients with motor neurone disease/amyotrophic lateral sclerosis may help to maintain nutritional status and reduce muscle mass depletion.[19]

Therapeutic outcome

8 weeks post discharge

- Mr H's motor neurone disease progressing slowly. Continues to use lightwriter for communication and with a pureed diet and stage 2 (mildly thick) fluids. No further reports of any chest infections.
- Weight relatively stable at approx. 72-73 kg, bowel movement and urine output good. Therefore meeting nutrition and hydrations requirements.
- PEG tube also allow medications or increased feed and fluid as his disease progresses.
- Feed with vitamin D may improve muscle strength and muscle function and may help reduce the risk of fractures and falls as mobility likely to decrease as disease progresses.[15-18]
- 15 g fibre in 1000 ml Fresubin 2 kcal HP Fibre is beneficial to maintain gut physiology.[13,14]