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Motor neurone disease

Enteral feeding and end-of-life care

This article explores the clinical rationale for enteral feeding (EF) in motor neurone disease (MND), methods of delivery, timing of intervention, outcomes, psychosocial implications and ethical debates, with a focus on end-of-life care.

MND is a group of illnesses characterised by degeneration of motor neurons in the brain and spinal cord, leading to progressive paralysis resulting from increasing muscle weakness, with no cure.[1,2] It can develop differently in each person and present with similar symptoms to other conditions, making a diagnosis challenging, particularly in its early stages.[1]

There are four main types of MND:

1. Amyotrophic lateral sclerosis
2. Progressive bulbar palsy
3. Progressive muscular atrophy
4. Primary lateral sclerosis

As MND progresses, dysphagia develops as a common complication resulting in malnutrition, dehydration and aspiration pneumonia.[3] Supportive treatment options, of which EF is one, can improve quality of life for MND patients. Decisions surrounding the initiation of EF, its continuation or withdrawal intersect with profound ethical and emotional considerations at the end of life.[4] Studies demonstrate that weight loss correlates with poorer prognosis and reduced quality of life.[5] EF can provide reliable nutrition and hydration and reduce aspiration risk.[6,7]

CLINICAL RATIONALE FOR EF

As a supportive intervention, the aim of EF is to enhance comfort and modestly prolong survival. Discussions with patients and family members need to provide consistent, realistic information so that the patient can make an informed decision about whether EF is right for them.

The most common route for EF is via a percutaneous endoscopic gastrostomy (PEG). However, a radiologically inserted gastrostomy ▶

(RIG) may be placed when decreased respiratory function makes an endoscopy procedure unsafe.[7] Some specialist centres provide a per-oral image-guided gastrostomy (PIGG) as an alternative enteral feeding option.

TIMING OF DISCUSSION AND INSERTION

An assessment of nutritional intake (including hydration) should be undertaken at diagnosis and at regular intervals through disease progression.[3,8] Guidelines recommend discussing gastrostomy early, before severe dysphagia or respiratory decline. However, due to challenges associated with the initial diagnosis, dietetic assessment, intervention and EF recommendations may be made while the patient is still undergoing investigations.[8]

Further discussion about EF should occur annually or more frequently if symptom progression occurs with a decline in nutritional status or if procedure risk increases.[8] Studies indicate that EF discussions between the patient and the specialist nutrition team (usually a dietitian and/or nutrition specialist nurse) have a higher prevalence of patients choosing to have a PEG, as well as having improved outcomes.[5,9] So too do multidisciplinary team (MDT) meetings to discuss patient progress and timings for PEG referrals.[5]

According to a recent survey of UK healthcare professionals (HCPs), one-third of clinicians thought that the first conversations about EF were held later than was ideal. Additionally, there was variation among HCPs regarding the topics discussed concerning EF and the timing of gastrostomy placement. HCPs concentrated more on day-to-day workings and expectations, and medical clinicians focused more on mortality.[10] In these discussions, it's important that the patient considers their advanced health directive and their wishes are included.

When a patient decides to proceed with a PEG, earlier insertion is associated with better outcomes, lower procedural risk and improved quality of life. Delayed insertion can lead to a higher 30-day mortality rate, increased length of hospital stay, fewer home discharges and an increase in healthcare-associated costs, particularly when forced vital capacity is <50% and/or the patient has had >10% weight loss.[5,7,8] Delaying discussions around EF and longer wait times for PEG placements may lead to it being too late to safely undertake the procedure.

Patients may oppose early intervention out of fear of medicalisation, so striking a balance between autonomy and clinical need is crucial. Moreover, it is important to have discussions with the patient and their family concerning opinions about ending EF. Ensuring the family is aware of the patient's wishes decreases anxiety and fear.

CLINICAL OUTCOMES AND IMPLICATIONS

A systematic review showed an increased incidence of major complications post-PEG insertion when the procedure was undertaken in those with more advanced MND.[2] EF does not alter disease progression and outcomes vary in terms of length of survival after the procedure; people with limb onset have the longest survival time after PEG placement.[9]

Patients report that transitioning to EF has profound psychosocial implications:

- **Loss of normal eating:** Mealtimes are social rituals and EF may feel isolating.
- **Family dynamics:** Caregivers often experience relief from reduced mealtime stress for the patient, but their own nutritional intake may be impacted as they move to potentially preparing meals for one.
- **Patient autonomy:** Some view feeding as prolonging suffering, others as preserving dignity.
- **Communication challenges:** Declining speech complicates discussions about feeding preferences.

Patients can feel that an opportunity to make life choices is taken away from them once they receive an MND diagnosis. EF as a treatment option can allow the patient to feel they have a choice in how they wish to proceed within their disease progression in terms of agreeing (or not) to EF, and if and when they wish to stop feeding. This can lead to ethical questions.

ETHICAL DIMENSIONS TO END OF LIFE

Ethical dilemmas with EF include (but are not limited to): [3,4,11]

- **Autonomy versus benefit:** Clinicians must respect patient choice while promoting well-being.
- **Informed consent:** Patients should understand the risks, benefits and alternative options, should there be any for their specific case.
- **Withdrawal of feeding:** This is ethically permissible if it aligns with the patient's wishes and is one of the most challenging aspects of EF in MND.
- **Advance care planning:** Early documentation of preferences can prevent crisis decisions and emotional distress.

A patient may have doubts or change their mind about EF as their condition deteriorates. Any change in decision must be discussed and documented. All members of the MDT must be aware of any change in treatment plans.

In end-of-life care, continuing EF

can provide comfort by preventing hunger and dehydration, facilitating the delivery of medication and prolonging survival, although this can be at an increased cost of dependency.[6,11] In some cases, feed tolerance can deteriorate, and patients may decide to continue feeding but at reduced volumes and/or rates.

The withdrawal of EF is legally and ethically permissible[10] and patients may feel that continuing to feed no longer aligns with their values.[4] It is imperative that clinicians listen to their patients' wishes and desires around continuing or ceasing feeding, and that patients don't feel they have been pushed towards making a decision one way or the other. This can be difficult if the wishes of family members differ from those of the patient, whereby a patient feels pressured to continue feeding to reduce distress to family members. Palliative care involvement can ensure symptom relief through mouth care and comfort measures.[4]

Patients can record feeding preferences in advance care directives[3] and it is important for HCPs to be aware of patient choices. This can lead to improved communication between clinicians, patients and family members, ensuring decisions reflect patient values even if communication is lost through disease progression.[12]

ROLE OF HEALTHCARE TEAMS

MDTs are vital to support patients and families throughout their journey with MND. Communication is key and MDT meetings to discuss updates or changes to the patient and their needs can ensure patients get the right support. Emotional counselling is vital to help families cope with withdrawal or continuation decisions,[4] although access to mental health services can be a challenge.

The majority of patients will fit under one of the following cases, highlighting diverse patient choices and the importance of individualised care:

- **Case A:** Early PEG insertion stabilises or increases weight; patient chooses to continue feeding at end of life for comfort.
- **Case B:** Patient declines PEG, prioritising social mealtimes despite weight loss and risks of choking and aspiration.
- **Case C:** Patient initially accepts PEG but later requests withdrawal, emphasising dignity over prolongation.

Feeding discussions should take place early post-diagnosis, preferably by an experienced nutrition team member. Nutrition assessments should occur at diagnosis and at regular intervals, ensuring the MDT shares communication and provides consistent advice to patients and carers.[10] Medical notes must be kept updated with patient preferences and advanced care plans,[3] and the team addresses the holistic needs of the patient. Support for the patient and their family also needs to be considered.[12]

CONCLUSION

EF can raise complex psychosocial and ethical challenges, particularly at end of life. Decisions about initiation, continuation or withdrawal must be individualised, grounded in patient autonomy and supported by multidisciplinary care. Ultimately, the goal is not merely the prolongation of life but the preservation of dignity and comfort in alignment with patient values.

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Questions relating to: Motor neurone disease

1 Describe the nutritional and clinical factors that should be considered when assessing the need for enteral feeding in a person with motor neurone disease (MND).
2 Discuss the benefits of early discussions about enteral feeding and explain how the timing of gastrostomy placement may influence clinical outcomes.
3 Outline the roles of the multidisciplinary team (MDT) in supporting decision-making and ongoing nutritional care for people with MND receiving enteral feeding.
4 Evaluate the evidence around the impact of enteral feeding on nutritional status, survival and quality of life in people with MND.
5 Discuss the challenges healthcare professionals may encounter when initiating conversations about enteral feeding and how these can be addressed using a patient-centred approach.

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6	Describe the ethical considerations involved in decisions surrounding enteral feeding and withdrawal of feeding in people with advanced MND.
7	Using examples from the article, discuss the psychological and emotional factors that may influence a patients decisions regarding enteral feeding.
8	Outline the potential complications associated with gastrostomy placement and describe strategies that may reduce procedural risk.
9	Explain the importance of advance care planning in people with MND and discuss how patient preferences should be incorporated into decisions regarding enteral feeding.
10	Discuss the role of the dietitian in providing nutritional support throughout the progression of MND, including end-of-life care.