

Oral Feeding Difficulties and Dilemmas

A guide to practical care, particularly towards the end of life. Report of a working party 2010. Royal College of Physicians and British Society of Gastroenterology.



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The take home message of this report is simple. Insertion of a PEG is not something to be undertaken lightly, and should only be taken after consultation with a full multidisciplinary team consisting of physician, dietitian, speech and language therapist and nurse, having provided the patient and family with appropriate information about the risks and benefits of PEG feeding and its alternatives.¹ Why is a report needed to state this simple fact? The answer lies in some shocking figures. The authors of the report quote one audit of 719 PEG procedures which demonstrated that 19% were futile and of those dying 43% did so within one week of insertion.² Even in the best units 30 day mortality is 6% with 10% morbidity.³

The underlying causes of this mortality and morbidity are simple to diagnose but may be complex to treat. In the 1970s large bore tubes were used for nasogastric feeding, which were poorly tolerated and rarely used for more than a few days. Gastrostomies were rarely performed and had significant morbidity rates. In the early 1980s fine bore nasogastric tubes and endoscopic placement of PEG tubes were introduced. Since then the number of PEGs inserted has increased enormously and it is clear that many are now inserted unnecessarily. Prevalence figures for enteral feeding in the community suggest that nearly 22,000 people are enterally fed at any one time. While the proportion with cancer continues to rise, 58% of these will have neurological diagnoses, with stroke being the most common cause, these patients will often have associated cognitive and communication deficits.¹

So why have numbers risen so high? A number of themes emerge from this document. Poor communication with families, failure to consider alternatives, and lack of relevant skills all appear to contribute. In the acute setting, a relatively common scenario seems to be family distress at a sick relative's being 'starved', when PEG is seen as a solu-

tion. Careful explanation of the alternatives is essential here. In many cases, if the patient is not hungry then nothing further needs to be done. If swallowing is impaired, then careful definition of the risks, altered consistencies, safe swallowing techniques and hand feeding, taking enough time to do this properly, may be appropriate. If feeding support cannot be offered this way, or if it is needed for less than six weeks, then an NG tube may be the appropriate choice. Taking the time to make a careful multidisciplinary decision with family and patient involvement is critical.

The report recommends that a multidisciplinary nutrition support team of healthcare professionals, ideally but not inevitably led by a doctor with special expertise in nutrition, also consisting of a nutrition nurse specialist, dietitian and speech and language therapist, and involving the GP and any community team, that is in a place to obtain the best results. Although this is feasible in hospitals, it is clearly more difficult to implement within the community. Dietitians and nutrition nurse specialists are not readily available in all community teams. Management structures do not always facilitate timely discussion of the issues. Although in principle NG tubes may be more appropriate for patients needing them for less than six weeks, ensuring they are correctly positioned before each feed is difficult, and replacing a dislodged tube may involve distressing visits to A&E for replacements if community staff feel they haven't the skills. This is of particular relevance to the nearly 7,000 people with PEGs in nursing and residential homes.

Despite these issues the report can at times appear unduly negative about PEG feeding. A section addressing the negative aspects of PEG feeding highlights not only the 30 day mortality, but also social consequences for the patients including the fact that patients can be deprived of the pleasure of eating. This seems to be based on an

Too many PEGs are inserted resulting in unnecessary morbidity and mortality. Careful oral feeding may result in better quality of life for patients and carers

assumption that insertion of PEG equates to 'nil by mouth'. This is clearly untrue. PEGs may be a source of augmentative feeding when eating is tiring or takes a long time; eating small amounts can then be used as a source of pleasure. Although it is true that a PEG can remove meal times as a source of structure for the day and social interaction, from a carer's perspective hand feeding, which takes a long time and is associated with a risk of coughing, can be extremely stressful. In addition rehabilitation interventions now focus on repetitive practice, this applies to swallowing as much as to walking or dressing.⁵ Patients with PEGs (or NGs) inserted who might expect a slow recovery need to continue practice swallowing, at first with a skilled speech and language therapist paying attention to safe swallow techniques and then by a trained carer.

Even when these issues are addressed, the placing of PEG tubes can involve complex ethical decisions. The third chapter of this document is an excellent summary of the complex ethical issues. The arguments advanced consider many basic principles and are applicable in situations beyond the dilemmas posed by oral feeding. Issues such as sanctity of life, the intrinsic and instrumental value of life, the principle of ordinary and extraordinary means intended and foreseeable consequences are

discussed. The very topical issues surrounding withholding and withdrawing life prolonging treatment, and best interests decision making, euthanasia, killing and letting die are also considered. The role of the mental capacity, best interest decision making and surrogate decision making are also considered. The distinction between medical treatment and basic care is considered with the report acknowledging the consensus view of the courts, professional bodies and the overwhelming majority of ethical and medical opinion is that nasogastric or gastrostomy feeding is medical care. The detail in this chapter highlights the complex issues that may need to be considered when making decisions in difficult and challenging clinical situations. This chapter is followed by a comprehensive review of the legal considerations, reviewing issues now familiar to many clinicians such as capacity, and competence, and how best interests are determined.

In conclusion, this report is a timely reminder that PEG insertion should only occur after careful consideration of the risks and benefits with careful explanation of these and alternatives to the family. The benefits of PEGs, in carefully selected patients, to maintain body weight, as a form of augmentative feeding combined with judicious eating should also not be underestimated. ♦

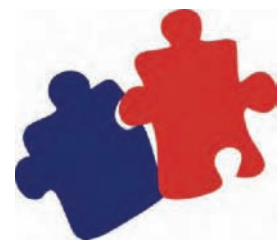
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