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Decision Making for Enteral Nutrition in Adult Patients with Dysphagia – A Guide for Health Care Professionals

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1. Introduction

A review of current literature reveals high mortality rates post insertion of feeding tubes for the provision of long term enteral nutrition, most specifically post placement of a percutaneous endoscopic gastrostomy (PEG). The recommendation of enteral nutrition is often a complex decision, which requires the consideration of many aspects, including not only the medical need for nutritional support, but also the wishes of the patient and their families. The provision of artificial nutrition and hydration can be an emotional topic which leaves many health care professionals uncomfortable and unsure of what recommendations to make. This chapter aims to provide information about the different methods of enteral nutrition available and the indication for each one. It also hopes to present a number of factors that need to be considered by all health care professionals who are involved in the recommendation of enteral nutrition.

Enteral nutrition is the provision of sustenance into the stomach or small intestine and includes tube feedings as well as oral nutritional supplements [1]. The focus here is on enteral nutrition via tube feeding.

2. Indications for enteral nutrition

Optimal hydration and nutrition is required to meet the body's daily nutritional requirements. Patients with dysphagia may be unable to attain these minimum nutritional requirements with oral intake and require enteral nutrition [2-9]. These patients include those who are unable to swallow due to neurological damage or degeneration [4, 10-15], or those who have structural abnormalities that make oral nutrition impossible, as in the case of patients with advanced stage head and neck cancer or oesophageal cancer [16-18].

The most common indicator for long term enteral nutrition is a cerebral vascular accident (CVA) [3, 5, 10-12, 19-26]. Dysphagia with resulting malnutrition and/or dehydration is common in patients who have had a CVA, explaining the high need for enteral nutrition within this population [10, 13, 27-28]. Patients with other neurological deficits such as traumatic head injury or neuro-degenerative diseases, may also require short or long term enteral nutrition as a safe method of hydration and nutrition [7, 29-33].

Certain medical conditions are more likely to predispose patients to require enteral nutrition because of concomitant dysphagia and increased nutritional needs. Patients with head and neck cancer may develop dysphagia after radiation treatment as a result of tissue damage to the swallow mechanism [18] with a resultant need for prophylactic enteral nutrition [17]. Those patients who continue on oral intake may require enteral nutrition as a supplement to ensure sufficient intake of the daily nutritional requirements while receiving radiotherapy [18]. In cases of trauma to the body or after surgery, enteral nutrition is also recommended to aid sufficient caloric intake to minimise loss of body fat and to support recovery [15, 29, 31-32, 34-35].

3. Enteral nutrition routes

There are different enteral nutrition routes, and the route chosen is determined according to the length of time and the type of enteral support needed for a specific patient. The different types of enteral nutrition include nasogastric tubes (NGTs) and nasojejunal tubes (NJTs); surgically placed gastrostomy tubes (GTs) and jejunostomy tubes (JTs); and non-surgical placement methods include percutaneous endoscopic gastrostomy (PEG) or percutaneous endoscopic jejunostomy (PEJ).

Before the development of the PEG procedure by Gauderer and Ponsky in the early 1980s, a gastrostomy tube was placed under general anaesthetic. PEG has become the most popular method of tube placement because of the ease of insertion, minimal invasiveness and no requirement for a general anaesthetic [36-38]. A surgical gastrostomy may still be performed in cases where PEG is not possible due to obstruction which makes the passing of the scope down the gastrointestinal tract impossible [39].

4. Short term versus long-term enteral nutrition

The placement of NGTs are recommended for the delivery of early enteral nutrition in the acute stages of disease [2, 10, 13, 40]. The benefits of early enteral nutritional have been documented within various groups of patients [41-44]. NGTs are for short term use only and should not be in situ for periods longer than 4 to 6 weeks [2, 15], as they can cause serious complications including nasal ulceration, chronic sinusitis and increased risk of aspiration pneumonia [15, 39, 45].

NGTs are easy to insert and require no surgical procedure or administration of anaesthetics for placement [10, 14, 46]. However they are poorly tolerated by patients, and are often pulled out after insertion thereby reducing the nutritional advantage which was the aim of placement [47-49]. NGTs may be placed incorrectly by the professional inserting them, with incidences reported to range from 0.3 to 27% (cited by [50] in [51]). A misplaced NGT may result in aspiration pneumonia which can be fatal [51]. Patient positioning, with most hospitalized patients being in a sedated state or lying flat, during NGT feeding can also result in aspiration pneumonia [52-53]. An increase in reflux with NGT placement has been noted [39, 46] particularly in cases with pre-existing gastro-oesophageal reflux [54]. Similar negative effects have been noted with the use of PEGs [46].

If a patient requires enteral nutrition for a period longer than 4 to 6 weeks, and the prognosis justifies the intervention, placement of a gastrostomy or PEG tube for the provision of long term enteral nutrition could be considered [14, 19, 55, 56]. However, Maitines et al. (2009) suggest a longer period of at least 6 to 8 weeks with an NGT in situ, before considering a PEG to ensure a better outcome. Others [14] consider the prognosis and argue that a patient at the end stages of a disease should not be considered for PEG but should rather receive nutrition via NGT. No difference between NGT and PEG cohorts was found in the rate of complications [46], the rate of mortality post placement [45-46] or the occurrence of pneumonia post placement [46].

Higher complication rates for gastrostomies relative to PEG placements have been reported [57-58]. Complications include internal leakage, peritonitis, fistula, dislodgement, external leakage and skin infection. Higher mortality rates in surgical gastrostomy cases (29%, n=35) compared with PEG cases (17%, n=12) were not significantly different [58].

The reasons for high mortality rates include poor patient selection. Patients with risk factors for mortality have been recommended for a PEG resulting in poor outcomes that are being linked to the PEG procedure, when in fact these patients were at risk of death regardless of PEG placement [59-60]. There is strong evidence linking certain underlying medical conditions to higher mortality post PEG [5, 15, 36, 55-56, 59, 61-63]. The highest mortality rates occurred in patients who had CVA and malignancies [22, 62].

The timing of PEG placement [24, 64] is noted also to affect the outcome. It has been suggested that there be a 30 day delay in the placement of long term enteral nutrition to ensure a better chance of survival, leaving patients on short term enteral nutrition for a longer period [24, 64]. The notion of poor timing in the placement of PEG is linked to poor patient selection. If a patient has an underlying medical condition that places them at risk for mortality, it can be argued that they would have died regardless, and early PEG insertion, at a time when they are at risk of death due to an underlying medical condition, means that they die with a PEG in situ which makes their death a statistic of mortality post PEG placement. To counteract early PEG placement, it is suggested that if a patient has survived and still requires a PEG after their condition has stabilised, only then should it be considered. Abuksis et al. (2000) noted a lower mortality rate in patients who were deferred for the placement of a PEG until they were discharged from hospital and if it was still required at 30 days post discharge.

As an example, mortality in patients with CVAs usually occurs in the acute stage when a patient is still in the hospital [65]. Dysphagia is common following a CVA [65] and many CVA patients will regain their ability to swallow within two weeks post infarct [66]. A patient who receives a PEG at this stage is at high risk of dying due to the underlying medical condition of a CVA [65]. The high mortality will be reflected as a consequence of PEG placement in cases with a CVA. The timing for the placement of a PEG in a patient with a CVA is critical, and should only be considered if a patient has not regained their ability to swallow within four weeks [13, 67]. During the acute stages post CVA, an NGT is recommended for the provision of hydration and nutrition [13].

There are also a series of risk factors such as increased age, decreased body mass index, a higher number of co-morbidities, and decreased blood albumin levels have been identified as placing a patient at greater risk of mortality post PEG. Along with the primary medical condition and timing of placement, these factors also need to be considered when recommending a patient for a PEG to reduce the likelihood of poor outcomes. One such risk factor is increased age. Patients over the age of 60 were found to have the highest mortality rate at 30-days post insertion [20, 22-25, 55-56, 68-70]. Age together with diminished mental capacity, as with patients who have dementia, tripled mortality in the period after placement [22]. Such outcomes caution against PEG placement in older patients with dementia.

The positive outcomes of long term enteral nutrition should also guide decisions for such a recommendation. One such outcome post PEG placement is the ability to return to oral intake which can occur in patient populations with a range of medical conditions and depends on factors such as the presence of dysphagia, age, and the underlying medical condition that necessitated PEG placement [12, 17, 69]. Factors that determined a return to oral intake, were the ability to take some amount of nutrition orally at 3 and 6 months post PEG placement [12], regression of the tumour that had originally caused dysphagia post chemo/radiotherapy [12, 17] regaining of the swallow post CVA [12, 69], a younger age, the absence of dysphagia and intervention by a speech therapist to regain the swallow pre PEG placement [71].

The provision of nutrition into the stomach via NGT or gastrostomy/PEG is common [5, 21]. Gastrointestinal intolerance of tube feedings, identified by the presence of large gastric residual volumes, nausea and vomiting, ileus, abdominal distension, and diarrhoea [72], is a major factor limiting adequate enteral intake in patients. In cases such as these the stomach may be bypassed and nutrition delivered to a lower part of the gastro intestinal tract [4, 39, 73]. NJT/PEJ enteral nutrition has been noted to result in better energy intake due to improved absorption in the small bowel and a decreased risk of reflux related aspiration due to feeds being delivered into an area further away from the pharynx [74]. However, Davies et al. (2012) report no difference in energy intake and risk of aspiration between patients receiving enteral nutrition via NGT and NJT.

5. Decision making between the different routes of enteral nutrition

PEGs, GTs and NGTs have advantages and possible complications. The outcomes relate to mortality and improved nutrition. Adequate nutrition is linked to better medical outcomes

and survival [35, 73]. PEG is noted to be superior to NGT with regard to improvement in general medical outcomes [46] with NGT candidates being statistically more prone to intervention failure, such as tube blockage or leakage, feed interruption and recurrent displacement, than patients who were fitted with PEG, regardless of the patient's underlying medical condition [46]. With better provision of feeds when a PEG is used, better medical outcomes may be expected as a patient is more likely to receive adequate hydration and nutrition.

When patients who had a CVA were considered as a separate group from other medical conditions, neither NGT nor PEG were superior in the delivery of nutrition. The presence of dysphagia was the key indicator for mortality rather than the type of enteral nutrition used [36].

There exists debate around which method of enteral intake is best suited for patients with head and neck cancer specifically. A large majority of patients with cancer are malnourished throughout the disease process and require enteral nutrition [75]. Determining the optimal mode of enteral nutrition in this patient population bears consideration of the benefits and drawbacks. Sobani et al. (2011) reported PEG as being superior to NGT in that it resulted in greater weight gain and lower mortality, but others [76] note a lower clinical risk of complications, and a greater chance of returning to full oral intake after a six month period, with patients left on NGT rather than fitted with a PEG. It was argued that a patient with an NGT would be more eager to feed orally in order to progress towards removal of the tube because of the visibility of an NGT, which can be unsightly to some. Beginning partial oral intake made muscle atrophy less likely and sped up the return to full oral intake, compared to those receiving nutrition exclusively via a PEG [76]. In patients with dysphagia and a range of medical conditions including neurological fallout and head and neck cancer, Gomes et al. (2012) noted no difference in mortality rates post PEG or NGT placement.

Mortality rates after PEG placement has been reported to be low as a direct result of the PEG procedure [11, 77]. However, Malmgren et al. (2011) suggest that the mortality rate in the first few weeks post PEG placement is 'high' and ranges between 10% and 36% depending on sample size and medical conditions [5, 22, 55-56, 69, 78-79]. The greatest majority of patients died within a 30 day period post PEG placement and in patients with dementia, the mortality rate was as high as 54% [79]. The 30 day mortality rates were from both developed and developing countries where a variety of medical conditions were included in the sample.

Strong evidence links poor nutrition upon hospitalization with poor medical outcomes, such as greater incidence of morbidity and mortality [45, 73, 80]. Malnourishment is measured using the body mass index (BMI), with a BMI of <18.5 indicating malnutrition (WHO, 1995). Malnourishment can be as a result of the disease process or due to socioeconomic factors [81] and can be further exacerbated by hospitalization [13, 15, 35, 44, 48, 56, 73], because of interruptions in the provision of enteral nutrition, inadequate nutrition prescribed and the inability of a patient, who may be on oral intake, to physically eat independently [81]. Malnourishment at the time of PEG placement is a crucial factor noted to place a patient at risk for mortality [19, 45, 55-56, 70, 77].

Upon admission to hospital an NGT may be placed to improve nutrition before placement of a PEG [77]. But NGT feeds can result in minimal improvement in nutritional status because of interrupted feeds when the patient has a procedure, late placement and commencement of

30 day mortality rate (%)	Sample size (N)	Medical condition	Country	Researchers
15.8%	359	Head and neck cancer (n=97) CVA (n=73) Malignancy (n=61) Head injury (n=59) Cerebral palsy (n=38) Congenital anomaly (n=19) Motor neuron disease (n=7) Dementia (n=5)	Bosnia Herzegovina	Vanis, Saray, Gornjakovic & Mesihovic, 2012
22%	201	CVA (n=97) Malignant oesophageal obstruction (n=33) Dementia (n=16) Other neurologic disorders (n=13) Parkinsons (n=12) Other (n=23) Other malignancies (n=5)	Sweden	Malmgren et al., 2011
10%	77	Neurologic disorders (n=71) Head and neck cancer (n=6)	Turkey	Ermis et al., 2012
20%	128	CVA (n=34) Non neurologic cerebral hypoxia (n=30) Cranial tumour (n=23) Head and neck cancer (n=19) Motor neuron disease (n=13) Other (n=9)	Turkey	Gundogan et al., 2014
19%	83	CVA (n=83)	Norway	Ha & Hauge, 2003
22%	112	CVA (n=33) Head and neck cancer (n=27) Chronic neurological disorders (n=22) Other (n=30)	Britain	Longcroft-Wheaton et al., 2009
18.5%	187	Malignancy (n=187)	USA	Keung et al., 2012
36%	61	CVA (n=50) Dementia (n=21) Malignancy (n=9) Head and neck trauma (n=3)	Israel	Abuksis et al., 2004
28%	361	CVA (n=120) Dementia (n=103) Oropharyngeal malignancy (n=65) Other (n=73)	USA	Sanders et al., 2000

Table 1. International mortality rates 30 days post PEG placement

feeds or accidental removal of tubes [47-48, 72]. A nutritionally compromised patient would benefit from placement of a PEG with the aim of improving nutrition, based on evidence that PEG placement facilitates better improvement in nutrition [5, 75]. However PEG placement comes with a high risk of mortality due to the patient's initial poor nutritional status.

Based on the high mortality rate of malnourished patients, it is important to consider the nutritional status of individuals prior to PEG placement [19, 45, 55-56, 70, 77]. A review of the literature suggests that albumin levels may be used as a marker of a patient's nutritional status [82]. Albumin is a protein made by the liver, and is a measure of protein in the body. Albumin balances the amount of blood flowing through the body's arteries and veins and helps to transport calcium, progesterone, bilirubin and medications through the blood. A serum albumin test will measure the amount of protein in the blood and can be used as an indicator of the presence of liver or kidney disease [83] which can affect patient survival. Normal levels of albumin are considered to be in the range of 3.4-5.4 g/dL or 35-50 g/L, depending on how specific laboratories measure it. Blomberg et al., (2011) noted the link between low albumin levels pre-insertion of PEG and a high mortality rate post insertion. This link confirms that hypo- albuminaemia is a risk factor that should be considered in all patients being medically worked up for PEG placement [45, 56, 59, 77, 84]. Co morbidities like diabetes and cardiac disease were also noted to be significant risk factors for high mortality in patients post PEG placement [19, 56, 59, 70, 82].

6. The role of the speech language therapist (SLT)

Evidence exists to support the involvement of an SLT in the assessment and treatment of patients with dysphagia. Langmore et al. (2011) [108] suggested that it is important for an SLT to assess a patient with head and neck cancer and to determine the most optimal approach for each patient to be able to recover swallowing or to compensate for losses due to surgical or chemo-radiation intervention. The role of the SLT in the management of patients with dysphagia who may require enteral nutrition, is not to recommend the route of enteral nutrition, but rather to make a recommendation of whether or not the patient can eat orally and is safe to do so. All discussions and decisions relating to enteral nutrition, whether short or long term, should take place within an inter-professional team including the patient and caregivers.

Considering the multitude of risk factors that exist for poor outcomes post PEG insertion, it follows that a patient should be individually assessed for the presence of any risk factors before being recommended for the procedure [85-87]. A comprehensive assessment by the team needs to consider factors such as: 1) the potential benefits to the individual should they receive a PEG, 2) biochemical parameters, like blood albumin level, 3) multiple comorbidities, 4) prognosis, 5) and the presence of risk factors that may place a patient at risk of mortality post procedure, such as being over the age of 60 years and a low BMI [10, 19, 23, 25, 45, 56, 69, 87-89, 90].

Strong emphasis is placed upon a team approach when assessing patients who may be recommended for long term enteral nutrition [85-87]. A rigorous assessment, by a team, for each patient being considered for a PEG ought to be in place. The team needs to ensure that all risk factors which could affect outcome are considered and that an informed decision respects patient autonomy [60, 85-87]. A patient who is considered a high risk for mortality should not be considered a candidate for the procedure as it would be a futile intervention. Better patient selection would improve the outcome of patients who are recommended for and fitted with a PEG [91].

7. Ethical considerations

A patient may refuse a NGT or a PEG procedure and wish to begin/ continue oral intake, even if it means a shorter survival period. Patient's decisions need to be honoured and respected by health care professionals [92].

Where patients opt for enteral nutrition, despite the benefits that enteral nutrition can provide a patient, such as improved nutrition and a longer survival time, quality of life is affected [93]. Health care professionals should counsel patients on the effects that a PEG tube will have on their quality of life [94], by shifting the focus of management post PEG insertion to include social aspects and not only clinical needs [95].

The placement of a PEG for the provision of enteral nutrition is considered a life-saving procedure in some cases [93, 96] and many patients who have a PEG attest to this fact and the benefit that PEG feeding provides them [96-97]. One study noted particularly positive patient reports on their experiences living with a PEG tube, with 84% (N=51) noting a positive or neutral effect of the tube on their lives, 90% (N=51) expressing a view that the tube was worthwhile and 96% (N=51) noting that they would recommend it to another patient [97].

Negative experiences that a PEG has on patients' quality of life have been extensively reported. Common difficulties associated with having a PEG tube, which affect quality of life, include a high level of complication, like tube blockage, leakage and discomfort [94] interference with family life, social activities and hobbies [93-94, 98-99], interference with intimacy [94], negative reactions from others [95], a burden placed on family or caregivers [95] and a feeling of missing out on meal times and food [95]. Similar negative effects on quality of life are reported in patients who receive NGT feeds [98]. A study in Taiwan noted that the majority of patients are discharged home on NGT feeds because of a refusal to have a PEG placed [100]. Reasons included concern over leakage and infection following a PEG, a worry that the patient is too old and frail to undergo an operation and a cultural belief that the patient will not die "whole" if they have a PEG in situ [100].

In light of the high mortality rate post PEG placement, the concept of futility bears discussion. Futility refers to a medical intervention that would have no effect, or if there was an effect, it would not be one that the patient benefitted from [89]. Many patients receive long term enteral nutrition where no effect or benefit is proven in terms of nutritional improvement or survival

[56]. All aspects linked to possible mortality must be considered, and risks and benefits weighed before a recommendation for enteral nutrition is made. If a patient is considered to be a high risk for mortality, certain procedures that will cause further suffering and no benefit may be deemed futile [7], and should be avoided [21]. The decision to place a PEG should be based on the perceived benefit it will bring to the patient [89] and if no benefit is presumed, then the procedure should not be done. A patient who is identified as a high risk for mortality post PEG placement should not receive a PEG but rather they and their families should be counselled on the risks that exist and the reasons for deferred placement. A team can make a recommendation for enteral nutrition based on their knowledge but a cognitively intact patient must make the final decision after being fully informed about the benefits and risks involved in the proposed management plans [89].

The issue of futility in PEG placement is most particularly noted in the case of patients with advanced dementia being fitted with a tube for the provision of long term enteral nutrition [101-102]. In this population, the placement of a PEG has no benefit to the patient and can actually lead to decreased survival due to complications, such as aspiration, that result from the placement [89, 102]. The use of long term enteral nutrition in patients with malignancy, with the aim of nutritional gain, needs to be questioned as there is no real nutritional gain in these patients post placement [16, 62, 78].

Azzopardi and Ellul (2013) suggest that, in certain patient populations, the insertion of a PEG will only prolong a life which is of poor quality and it needs to be determined through discussion whether this decision is ethical. A consideration in South Africa particularly, is whether it would be appropriate to perform futile procedures in a resource constrained public hospital sector [103]. If PEGs are placed in cases where patients have poor prognosis and are considered high risk for mortality post PEG placement, an argument could be made that the scarce resources would be better directed to those patients with potentially better outcomes.

The use of protocols in patient care ensures adherence with best practice. They are important documents to which health care professionals should refer to guide practice that will result in the provision of the best possible care [104]. Protocols for the assessment and management of patients with dysphagia who require enteral nutrition exist [2, 38, 66, 105] but do not include considerations like assessment of risk factors to justify the PEG procedure. Further, adherence to protocols cannot be assumed. The presence of risk factors in patients do not always deter health professionals in making a recommendation for PEG placement, as is evident by the persistence of high mortality rates, despite the known effects of risk factors and their effect on mortality [56].

8. End of life and enteral nutrition

The decision to refer a patient for a PEG placement or not, includes holistic consideration of many factors to make a recommendation that is in the best interests of the patient.

The provision of hydration and nutrition at the end of life care is an area of debate and can become a highly emotional topic. Delege et al. (2005) suggest that the decision to place a

feeding tube consider the basic principles of professional ethics. Informed consent from an adult who is cognitively intact is imperative, and the benefits of the placement of enteral nutrition must outweigh the risk of the procedure, which should cause the patient no harm [89].

The concept of palliative care needs to be introduced as a real alternative for patients who are not considered candidates for PEG placement due to the presence of risk factors that place them at high risk for mortality. The World Health Organisation (2002) considers palliative care as “...an all-encompassing approach to care that begins months or years before death”. PEG placement does not always benefit the patient, and although the actual PEG procedure does not harm the patient, the risk of mortality post placement is high, which in turn is harmful to the patient. The choice of refusing a PEG and remaining on oral intake as a form of palliative care should be made available to all patients and their caregivers, with provision of education and support for the decision they may make. The inclusion of a palliative care option for patients who do not wish to have a PEG placed would provide them with an alternative option, and it would also ensure that futile procedures are avoided which would uphold medical ethics.

The decisions around the recommendation of enteral nutrition, particularly in very ill patients who have a poor prognosis, are not easy for health care professionals to make. Clear guidelines that are based on evidence are crucial in order to help health care professionals navigate these difficult decisions that are often clouded with human emotion.

A role not often considered by SLTs is that of palliative care. The provision of artificial nutrition and hydration (ANH) to patients who are in the end stages of disease is debated, and can evoke emotional responses [106]. It is common for patients in the end stages of disease to have little or no oral intake [106]. Many practitioners may feel that depriving a patient of hydration and nutrition is unethical and can make health professionals uncomfortable [89,107]. A study of nurses’ perceptions on ANH in palliative care yielded more clinical reasons for withholding of ANH than for providing it [106]. Reasons supporting provision of ANH were emotive, not based on clinical fact and were not in the best interests of the patient [106].

In practice, there comes a time, when a decision needs to be made about the hydration and nutrition needs of a patient in the end stages of disease. The SLT is often the professional who, based on the assessment of the patient’s swallowing, is in a position to determine the feasibility of nutritional intake. It is important that the SLT and the inter-professional team are educated in the field of palliative care and ANH [106-107] to contribute to making an informed decision regarding a patient’s options at end of life and reduce the number of inappropriate referrals for futile procedures with poor outcomes.

9. Conclusion

Based on a review of current literature some important points have been raised around the recommendation process for enteral nutrition in adult patients with dysphagia. The key focus in any decision making process for medical procedures should be on patient autonomy. If a

patient consents to placement of a PEG for the provision of long term enteral nutrition, with a full understanding of the impact it will have on them, not only medically but socially and emotionally too, then a standard assessment procedure needs to follow. Assessment should be carried out by a team of health care professionals, including the SLT, and should include a consideration of the patients underlying medical condition, indication for PEG, prognosis of survival post procedure, age, nutritional status, the presence of co-morbidities and biochemical parameters. Based on the assessment findings, the team, in conjunction with the patient and their family, need to make a recommendation. If a patient is considered to be a high risk for mortality following PEG placement then alternate methods of intake need to be discussed with and recommended to the patient and their family, with education and counselling provided on the benefits and risks of oral intake as a form of palliation. A thorough assessment procedure will help to ensure that futile procedures are avoided and only patients who consent to and who will benefit from PEG placement are recommended for the procedure.

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