



Acute Training Solutions

PEG Feeding - Case Studies

Case study 1: Where a client is able to give consent

A 42-year-old female has severe athetoid cerebral palsy and a history of chest infections due to aspiration. She lives in her own home supported by care staff. There is a history of low weight and weight loss (Body Mass Index (BMI) 13). Videofluoroscopy has shown she is at significant risk with liquids and all textures. The SLT has recommended that non-oral feeding be commenced using enteral tube feeding. The dietitian and SLT worked jointly with the client to give her the opportunity to demonstrate capacity to consent using the following approach:

- Pictorial information to explain the treatment
- Sufficient time to understand the information about the procedure, risks, benefits and implications
- Opportunity to ask questions

Consent from Client

Q: If the client gives consent, how can you be sure they understand what they are agreeing to? It is not enough to assume that they are consenting by attending your clinic or present at a domiciliary visit.

Consider:

- Does your client understand the information they have been given?
- Does your client fully understand the implication(s) of your intervention?
- Does he/she have the ability to make an informed decision about treatment?
- Do you have the skills and knowledge to make this assessment of capacity?

These are just some of the questions you will need to ask before starting to treat a client who has LD. You may need the support of one or more of the following (and the carer) to assess level of understanding and how the client communicates:

- Speech and language therapist (SLT)
- Clinical psychologist and/or
- Specialist learning disabilities multidisciplinary team (MDT). They may be able to assist with providing information in an accessible format to either help the client make their choice or determine if they are able to do so.
- It is important to remember that a client should not be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success at Home Enteral Tube Feeding for Adults with a Learning Disability

Consider:

If the client refused this intervention, what would be the consequences? The client with capacity is able to make "unwise" decisions and have these decisions upheld. Care should be taken as some clients may be unable to give consent due to communication problems, but still have capacity to make decisions. The team must make careful assessment of each individual case.

If a client does not have capacity to make an informed decision then first consider whether the carer, relative or social worker has legal guardianship or power of attorney which entitles them to consent on specific issues on behalf of the client.

If yes, then the relevant paperwork will be required to be put in place for each specific treatment. The MDT team should explain the treatment options and gain consent from the client's legal representative.



Case Study 2: Client lacks capacity and has no legal guardian/power of attorney

The client is a 29-year-old female with PMLD requiring a spinal jacket/brace and is cortically blind. She has severe chewing and swallowing difficulties, is totally dependent for all care needs and lives with her elderly parents. She responds to tone of voice and enjoys being spoken to.

She is underweight with a BMI of 17 and does not manage to meet her nutritional and fluid requirements. She has major weight fluctuations associated with ill-health. She has been assessed as having a compromised chest with frequent chest infections and has commenced thickened drinks and puree diet.

Q: How would you progress with discussing enteral tube feeding?

As you are unable to directly discuss or ask her for her consent, use this checklist as a guide:

Decision making

- Are there any other (less invasive) alternatives to enteral tube feeding and have these been tried and documented?
- What is the aim of the intervention?
- Who will make this decision? Who would you need to consult (MDT /family/carers/ medical staff/advocate)?
- Is urgent action required due to acute clinical condition? If this is the case then it may only require the medical team to fulfil the legislative process for such situations.
- What information will the decision makers require?
- Will the treatment be of benefit or burden to her?
- Would she attempt to pull the tube out?

Practical issues relating to support

- What support will her family require?
- Will the care package need to be re-assessed to support the intervention
- Will her placement at home/day care/respite care be able to undertake the treatment in a safe manner?
- What additional tasks are required and who will undertake these?
- What are the training needs and how will these be met?
- What support is needed around eating and drinking skills? Consider involvement with SLT to work on skills and oral function.
- What additional equipment will be required? Consider all aspects of equipment not just ancillaries for enteral tube feeding e.g. adaptation of her spinal jacket/brace for feeding tube access.
- What are the barriers, if any, to enteral tube feeding and how can they be addressed?

The Role of Advocacy

An advocate enables a client to get their views across. They may be a friend, family member or independently appointed following a referral to an advocacy group or services. Anyone can advocate on behalf of an individual but if they are emotionally involved with the client, impartiality may not be possible. The advocate should contribute to the decision making process on the client's behalf however where conflict occurs it should be remembered that their views whilst listened to, have no legal status in relation to consent.

In some cases their views may conflict with others who are in the decision making process. As the client's representative they should be included in client specific MDT meetings to discuss what is perceived to be in the client's "best interests".

Case Study 3: Client is dependant on staff

A 43-year-old female, living in a nursing home, is totally dependent on staff for all her healthcare needs. She has severe PMLD with a neuro-degenerative condition, epilepsy and dysphagia. She is non-ambulatory, without upper or lower limb movements, apyrexial with the absence of infection. Dietary intake was modified to Texture C (BDA, 2002) and normal fluids.

Dietary assessment revealed food refusal and inadequate nutritional intake. She was unable to take the prescribed dose of oral anticonvulsant medication to control her epilepsy and suffered repeated chest infections due to downward aspiration.²² Home Enteral Tube Feeding for Adults with a Learning Disability

The predicted 24 hour energy requirement was 1200kcal. This was considerably in excess of her pre PEG oral intake and could have resulted in unacceptable weight gain. Due to her small stature and being non-ambulatory any weight gain could be predominately over her abdominal cavity thus impeding respiratory function.

Her energy and protein requirements were met with 400ml of a "Complete" 1 kcal/ml feed met. Her energy requirements were met for weight maintenance but the minimum requirement for sodium, potassium, chloride, magnesium, copper, selenium and vitamin B6 was not met. The feed was supplemented with a vitamin and mineral preparation to meet her Lower Reference Nutrient Intake (LRNI). There is a need for a suitable preparation complete in minerals and vitamins in liquid form suitable for administration via enteral feeding tubes. Energy $30 \times 8.3 + 846 = 1095$ Stress factor 010% DIT* and Activity 109 Total 1204 kcal Protein requirements 0.75g/kg 23.0g Fluid 30-35ml/kg 900-1050ml²³ Home Enteral Tube Feeding for Adults with a Learning Disability.

Protein

It is recommended to estimate protein requirements using stress factors (Todorovic and Micklewright, 2007). It is important to consider protein and micronutrient provision in a non-ambulatory patient with low energy needs where there is a high risk of developing pressure areas as the volume of feed required to meet energy needs may not always supply sufficient protein. A maintenance programme supporting pressure relief measures should be assessed and instigated by the appropriate member of the MDT (GPP).

Micronutrients and trace elements

Recommended micronutrient intakes are levels to prevent deficiency and are based on studies in the general healthy population (DH, 1991). In illness, requirements are likely to be raised (Shenkin, 2000). Micronutrients have a wide ranging function and suboptimal levels may impair function before signs of deficiency are seen.

Low serum Vitamin D levels were reported in 122 people with LD in a long-stay hospital ward in Hong Kong in 2006 by Fu Wong and colleagues (Fu Wong et al., 2006). Institutional lifestyle was reported to be a cause of low Vitamin D however for non-ambulatory clients the risk of such a deficiency still remains. Biochemical evidence of macro and micronutrient deficiency has been highlighted in people receiving HETF (MacDonald, 1989; McWhirter, 1994; Bannerman, 2001) and copper deficiency (Oliver et al., 2005).

The volume of proprietary feed to meet and not exceed the energy requirements of people with very low energy needs may not provide the Reference Nutrient Intake (RNI), Estimated Average Requirements (EARs) or LRNI of all nutrients. Currently, evidence is lacking whether the RNI, EAR or the LRNI is more applicable to individuals with LD on HETF.

It is possible that protein, vitamin and mineral requirements parallel energy requirements but the literature search did not reveal evidence of the micronutrient needs of this unique population. A similar dilemma has been reported by Carter (2006) in children with severe cerebral palsy.

The dietitian is best placed to assess the individual's nutritional intake, requirements and potential deficiencies. It is important to inform the professional with overall responsibility for medical care – usually the GP or consultant – about the findings of nutritional assessment with suggestions for appropriate action to safeguard the person's nutritional status (GPP).

Even though it is prudent to aim to meet RNI, the LRNI is appropriate to achieve for a small sub group of the population. Confirmation of nutritional status by biochemical monitoring may be necessary if the nutrient intake does not meet minimum requirements or clarification is required. If requirements cannot be met with prescribed feed alone, then supplementation including electrolytes may be required. 24 Home Enteral Tube Feeding for Adults with a Learning Disability

Fluid



Particular care needs to be paid to fluid balance as clients with LD are more at risk if they are unable to communicate signs of dehydration (Dickerson and Brown, 2005). There may be a need to compensate for additional losses, for example if client is a mouth breather or does not swallow their saliva. Fluid requirements are estimated as per standard protocol (Todorovic and Micklewright, 2007) and adjusted according to individual client need. Constipation and diarrhoea will also increase requirements. Detection and prevention of dehydration rely on subjective and biochemical monitoring as Carbamazepine, for example, lowers serum sodium (Dickerson and Brown, 2005).

The long-term (over) use of phosphate enemas can also lead to dehydration (MacDonald et al., 1989). Conversely, over-prescription of enteral tube feeds can result in fluid overload, reflux (oesophageal/gastric) with associated upward aspiration and undesired (and rapid) weight gain which can compromise respiratory function and mobility.

Other issues to consider during assessment

Re-feeding Syndromes

NICE (2006) gives guidance for identifying, addressing and preventing re-feeding syndromes though local guidelines may be in place in relation to the more well-known classical "Re-feeding Syndrome" (RS). However be aware that the risk in the LD population may be higher than the general population because of severe and prolonged under-nutrition and chronic inadequate nutritional intake. There is no evidence to support this in literature.

In classical RS the biochemical abnormalities which can arise when feeding is commenced include:

- Hypokalaemia
- Hyperglycaemia
- Hypomagnesaemia
- Hypophosphataemia
-as well as clinical abnormalities such as cardiac failure and acute circulatory fluid overload.

Wernike-Korsakoff Syndrome is caused by acute thiamine deficiency and clients should be managed as for RS but with high doses of intravenous doses of thiamine and other B vitamins for three days. Readers are advised to read Section 6.6 of the NICE Guideline 32 (2006A) for more information on re-feeding syndromes. Prior to initial feeding tube insertion the risk of RS should be assessed as per local guidelines (GPP).²⁵ Home Enteral Tube Feeding for Adults with a Learning Disability

Medications

Clients with PMLD in particular take a large number of medications to control mood, behaviour and epilepsy on a daily basis as well as pro nata (prn) (also known as "rescue" medication). Some medications have a direct impact on nutrient absorption such as anticonvulsants and osmotic laxatives (see Table 3). Neuroleptics (antipsychotics) cause pharyngeal weakness and dystonia, whilst some of the tricyclic antidepressants such as Amitriptyline, have an effect on saliva production resulting in xerostomia (dry mouth). Medication reviews are important to discuss the impact of new drugs as well as the continued combination of current medications. Staff are recommended to refer to Administering Drugs via Enteral Feeding Tubes: A Practical Guide and associated leaflets for patients, carers and general practitioners (BAPEN).