

Home Enteral Tube Feeding for Adults with a Learning Disability

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And last but by no means least our clients and their carers.

"It's important to treat her as you would anyone else, to be treated as well as anybody. By that I mean as a person who is ill and who has a disability. Not to see the disability before anything else; not to think there is nothing there worth the bother. She is a person first, the same as you, as anybody. You need to know that."

(A parent)

Executive summary

This Consensus Statement is intended to inform and support the practice of dietitians who are not undertaking a specialist learning disabilities (LD) role but do care for adults with a LD within their caseload. The Statement may be a useful resource for other professionals and student dietitians.

It is well documented that most people with LD have greater health needs than the rest of the population including mental illness, epilepsy, physical and sensory limitations, dental disease, thyroid disorders, heart disease, dysphagia, obesity and under-nutrition (Welsh Office, 1996; Kennedy, 1997; Bryan et al., 2000; DH, 2007A; NPSA, 2004; Bernall, 2005; Melville et al., 2005).

The health gains associated with good nutritional care include improved quality of life and improved disease outcomes (Astor and Jeffreys, 2000; DH, 2004). Whilst papers investigating specific benefits relating to adults with LD on enteral tube feeding and their carers were not found during the period of the literature review, the following extracts from interviews with carers echo some of the positive outcomes noted in the literature for other client groups (Peterson et al., 2006; McGrath et al., 1992):

"He is much happier now and laughs out loud and he has put on a bit of weight. It's easier for me as I can eat, as I am not feeding someone else at the same time."
(A parent)

"Disappointing to know he needed the PEG as he loved his food. But hand on heart thankful it needed to be done as we know now he won't choke. [It] has taken away the 'fear factor' for him and the staff. Caring for him was very stressful and distressing. [It's a] bonus for everyone."
(A carer)

The literature review revealed a dearth of research in the area of enteral tube feeding within this unique client group. Evidence was found to support five of the 15 key questions designed to inform the focus for the search. Details on recommendations for future research can be found in the Summary & Conclusion.

The Statement, though of some length, contains information which the authors feel is relevant to the client group and highlights particular differences in approach for the practitioner to consider. Wherever possible, signposting to acknowledged gold standards of dietetic practice are made throughout the document and Good Practice Points (GPP) are indicated within the text.

1.0 Introduction

1.1 Scope

This Professional Consensus Statement has been developed as a good practice guide for dietitians whose caseload includes adults who have a learning disability, living in the community and have a clinical need for enteral tube feeding.

Though the majority of clients will have in situ a gastrostomy tube and receive total nutritional support, many variations exist. Gastrostomy feeding may be adjunctive, used ad-hoc to provide nutrition and/or hydration and/or medication post-epileptic seizure or during periods of challenging behaviour where food and/or fluid refusal may be the presenting clinical picture (Burton et al.,2008). The most common type of enteral feeding tube used is a PEG tube but some clients due to their complex conditions may not tolerate an endoscopic procedure therefore require assessment for a Radiological Inserted Gastrostomy (RIG). It should also be noted that as more children with LD are making the transition to adult services, many have undergone fundoplication and often require a different route of feeding such as a Jejunostomy. The numbers of these seen in the community setting is increasing. As Percutaneous Endoscopic Gastrostomy (PEG) is the most frequently placed enteral feeding tube for long-term use (NICE,2006) for this reason we have focused on PEG within this document.

People who have a learning disability are nutritionally vulnerable for a number of reasons. At one end of the spectrum, factors include social isolation, limited nutritional knowledge and budgeting/cooking skills of self and carers and reduced ability to understand and apply health messages.

At the other end are those with profound and multiple learning disabilities (PMLD) who are non-ambulatory and totally dependent on a range of carers. Many decisions regarding their health and social care may need to be made in their best interests. Physiological anomalies, polypharmacy, multiple diagnoses and dysphagia are also common amongst this client group (DH,2007A).

1.2 Definition of a learning disability

The definition of a learning or intellectual disability includes all of the following dimensions (WHO, 1992).

1. A significant intellectual impairment with an intellectual quotient (IQ) more than two standard deviations below the general population, i.e. an IQ below 70 on a recognised IQ test;

and

2. Deficits in social functioning or adaptive behaviour, i.e. how well a person's coping skills allow for the everyday social demands present within their own environment. Formal assessments include the Vineland Adaptive Behaviour Scales and the AAMR Adaptive Behaviour Scales;

and

3. Are present before adulthood i.e. age 18yrs;

and

4. Are life long.

There will be local variations on the above definition. For example the Health Inspectorate Wales (HIW) review of services for people with a learning disability highlights the use of IQ alone is not sufficient to define this population (HIW, 2007).

1.3 Specialist services/extended roles

People with LD have an expectation and a right to access core services as well as specialist teams for learning disabilities (DH,2007B; Bamford, 2005; LDAG,2001; Scottish Executive,2000). Whether living at home, which could be parental, supported/assisted accommodation or within a residential setting, support should be available by such specialist teams who help clients live an ordinary life within their local community. The division of what is considered core and specialist is not (and indeed should not be) clear cut and robust working relationships between both teams are essential for the provision of a seamless service for this client group. The registered dietitian is pivotal to service provision and the knowledge, skills and role of the specialist within LD include:

- Advising on nutritional requirements, particularly energy as evidence indicates that clients with a LD and an enteral feeding tube in situ have reduced energy requirements
- When assessing nutritional status, having the knowledge and experience to interpret height, weight and anthropometric measurements for this client group
- Working without established guidelines or procedure in relation to LD but always within locally accepted scope of practice
- Using a holistic approach to assess, problem-solve and ensure that health and social needs are met
- Using appropriate health facilitation skills within the therapeutic framework
- Contributing to the application of a legal framework
- Identifying, referring and working in partnership with health and social care colleagues, agencies and organisations
- Addressing inequalities in health and social care
- Advocating both formally and informally
- Using augmented communication
- Working in dynamic environments and with service users who display unpredictable or behaviours that challenge.

1.4 Methodology

This professional statement is based on a systematic review of the available literature undertaken between October 2006 and August 2007. The aim of the review was to look at the evidence supporting the assessment, monitoring, complications and ethical issues specific to adults who have LD, who require enteral tube feeding for nutrition and/or hydration and/or medication. Fifteen key questions were drawn up to focus the literature review (Appendix 2). The search strategy included the following databases:

Cochrane Library
Medline
EMBASE
CINHAL
PUBMED
AMED

The adoption of a consistent approach to the critical appraisal of the resultant documentation contributes to the robustness of this Statement. All reviewers followed the qualitative and quantitative guides to critiquing research (Ryan et al., 2007A, 2007B). The grading system for evidence based guidelines was also followed (Harbour and Miller, 2001). A cross-over system was employed in that papers were randomly allocated to two groups of reviewers (the authors) who independently appraised each paper. Cross-over occurred within each group to match outcome. Consensus of the critical appraisals was reached at the critical appraisal meeting of all reviewers in January 2008 before finalising the evidence tables in May 2008 (Appendix 1), referenced to the key questions (Appendix 2).

Seventeen papers were found which were directly related to the client group, of which thirteen were single case studies. Few were directly related to nutrition apart from energy expenditure which was investigated in five papers (a combined total of 66 participants). The literature review confirmed the authors' perception that little robust research had been conducted looking at the specific healthcare needs of this unique client group. See Evidence Table in Appendix 1.

1.5 User involvement

The Service Users Advisory Group was set up to ensure that people with LD can give their views about the services they use. Their first report, *Nothing about us without us*, (DH, 2000) seeks to re-affirm the importance of inclusion by advocating user involvement in service provision. Working in partnership with our clients should enable us to provide the best service within our resources, to meet the needs of our clients.

Experiences from carers for clients receiving home enteral tube feeding and who have LD have been included in the text. A range of dietetic and other professional colleagues have been involved in the peer review of this document.

In formulating this Consensus Statement the authors confirm they have followed the BDA Ratification Process (BDA, 2006).

2.0 Decision making

This section of the Consensus Statement aims to give examples of issues that may arise and guidance on how legislation is applied to people with LD. Legislation exists to provide a legal framework for decision-making on behalf of adults who lack the capacity to make specific decisions for themselves. It also provides the means for adults, with the capacity to do so, to plan ahead in the event of future incapacity.

Readers are recommended to refer to the relevant legislation pertaining to their geographical work base as legislation differs slightly between countries:

- **Scotland:** The Adults with Incapacity Act (Scottish Parliament, 2000)
- **England & Wales:** The Mental Capacity Act (DH, 2005)
- **Northern Ireland:** Seeking Consent (DHSSPS, 2003)

Relevant excerpts from the legislation are included here as it is core to the care for a person with LD.

The Short Reference Guide for Psychologists and Psychiatrists (BPS, 2007) is recommended as a brief summary of the main points of legislation and is a brief guide to its implementation for clinicians. This Guide is applicable to England & Wales. The following is extracted from the Guide:

“The Principles set out at the beginning of the Act guide the process of assessment and of substitute decision-making:

- A person must be assumed to have capacity until it is established that s/he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.
- When decisions are made on behalf of someone who lacks capacity, they must be made in his/her ‘best interests’.
- When decisions are made on behalf of someone who lacks capacity, the less restrictive alternative must be considered to attain the goal specified.

The Act defines capacity as follows:

An adult can only be considered unable to make a particular decision if:

He or she has ‘an impairment of, or disturbance in, the functioning of the mind or brain’, whether permanent or temporary;
AND He or she is unable to undertake any of the following steps:

- Understand the information relevant to the decision;
- Retain that information;
- Use or weigh that information as part of the process of making the decision;
- Communicate the decision made (whether by talking, sign language or other means).

The Functional Approach

A functional approach must be taken. This means that someone’s ability to make a decision is determined by assessing whether they can undertake the steps above; it is not determined by their diagnosis nor by the apparent wisdom of their decision. Decision-making capacity is decision-specific and time-specific.

Best interests

In considering what is in someone’s best interests when making a decision, the following should be taken into account:

- Whether and/or when the person is likely to regain capacity and whether the decision or the act to be undertaken can wait;
- How to encourage and optimise the participation of the person in the decision;
- The past and present wishes, feelings, beliefs, values of the person and any other relevant factors;
- Views of other relevant health, family, carer and social representatives. The decision should be perceived to be in the ‘best interest of the client and not that of the family or carers’.

Where a person lacks the capacity to make decisions about a change in accommodation or about serious medical treatment and has no family or friends, there is a duty to appoint an Independent Mental Capacity Advocate (IMCA) to help inform the determination of ‘best interests’.”

The Scottish Act allows for application of “Welfare Guardian”, who may be granted full or partial powers under the Act (Scottish Parliament, 2000). Should there be no welfare guardian, the general practitioner in consultation with the team may complete an “adults with incapacity form” which enables treatments to take place. In emergency situations the medical person can act without consultation of the team. In Northern Ireland, those close to the incapacitated individual should be involved in the decision making process as detailed in “Seeking Consent” (DHSSPS, 2003).

In instances where there is no legal guardian the decision should be reached with consultation of all health, family, carer and social representatives. The convening of a multidisciplinary meeting is good practice to allow all to participate in decision making. This must be documented.

2.1 Assessments

Assessments need to be carried out, and it is good practice to involve carers in the assessment process and to communicate openly (GPP). In order to treat, the issue of gaining informed consent must be fully explored.

2.2 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) (see Appendix 3). 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.

2.3 Case Studies

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

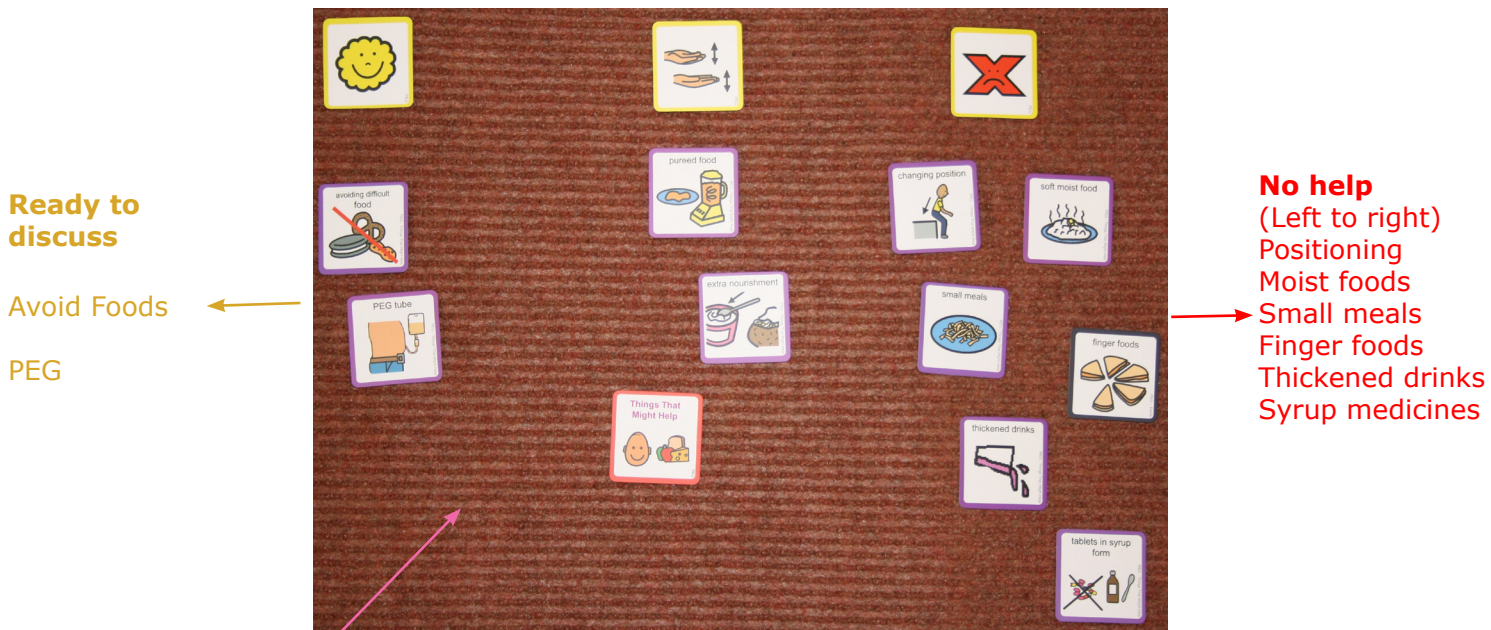
A 42-year-old female has severe athetoid cerebral palsy and a history of chest infections due to aspiration. She lives in her own home supported by care staff. There is a history of low weight and weight loss (Body Mass Index (BMI) 13). Videofluoroscopy has shown she is at significant risk with liquids 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
- The client was asked to demonstrate understanding, reasoning and recall using a "TalkingMats" format. A series of mats was used to explore concepts of meals, health and "things that may help" in relation to the client's swallow. Mat 3 is shown in Fig. 1 below.

Fig 1. TalkingMats format – Mat 3 showing 'things that may help'

Unsure about benefits of
puree food
fortified food



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Department of Psychology, University of Stirling

Theme Symbol - things that may help

This client felt that suggestions such as changing position, having small meals and so on (see red box) would not help her. She was unsure (middle column) about the benefits of having modified textures and supplementing foods to help stop her weight loss. After exploring these issues around problems with her eating and swallowing, the client decided to consider PEG placement (symbols under yellow smiling face). PEG information symbols were then used to focus discussion to help her make an informed decision (modified extract from TalkingMats & Alternative Eating and Drinking Booklet, AAC Research Unit).

A photograph of the TalkingMats was taken as evidence of capacity to consent to PEG feeding and recorded in the medical notes.

The following members of the MDT were also involved in this client's care:

- GP – responsible for medical care (this could also be a Gastroenterologist or consultant in charge)
- Social worker – to address changes in care package
- Care staff – to ensure package of care could be met
- Family – to enable them to understand the rationale for the treatment and to express their views.

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.

2.3.2 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 dependant 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:

(i) 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?

(ii) 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?

2.4 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".

IMCAs or Mental Health Officers (MHOs) in Scotland have undergone formal training as stipulated by the legislation. Such training enables them to assist with decision making in the best interests of clients who cannot make decisions by themselves, or with clients who have no family or friends who could be part of the joint MDT decision-making process.

2.5 Ethical issues: end of life – withdrawing and withholding artificial nutrition and hydration

The following is an extract from the British Medical Association (BMA) website. Readers are recommended to refer to the full document (BMA, 2007).

"The BMA's guidance on withholding and withdrawing artificial nutrition and hydration provides advice for health professionals about the range of factors that should be taken into account in making these difficult decisions. The guidance is very clear that oral nutrition and/or hydrations should continue to be offered to all patients who are able to swallow.

"Where there is a problem with the swallow it advised that careful thought be given as to whether artificial feeding should be provided or continued. The guidance is based on the premise that the primary goal of medicine is to benefit the patient."

It is essential where such decisions are considered that a multi-professional and multi-agency meeting be arranged together with key family members, advocate and any other significant others to discuss fully the concerns and agree on the best way forward. All discussions and decisions must be fully documented.

3.0 Meeting the client's needs

3.1 Establishing a client on an enteral tube feed

Establishing appropriate care and feeding regimens to best suit the client's needs and wishes includes extensive training and continual support to a multitude of carers. These are accessed within a variety of venues within the community.

Therefore to ensure continuity of care, effective training and education of both clients and carers is essential to the successful implementation of an enteral tube feeding regimen. The client's and carers' training needs should be assessed as early as possible.

It is documented that clients with LD accessing general practice can require up to quadruple the usual time required for consultation (Chambers et al., 1998). In a local audit undertaken in 2007 following the change of the enteral feeding pumps, the contractor recorded it had taken twice as long to re-train and change the pump for people who had a LD as compared to the general population. This was due to the complexity of the required individual care packages.

Twenty-nine different people including family and health care providers/carers from a multitude of agencies were trained (See Table 1).

Services such as day care and college may not have any experience with tube feeding and may view it as a threat or indeed not part of their traditional role. If perceived as a role extension then undertaking a risk assessment of this element of care which may also include an agreed competency based training programme would be necessary for HETF to take place in a supported care environment (GPP).

Table 1: Example of number of training contacts

Carer/ Venue	Relationship	Role	Training Pump	Bolus	Feed Regime /Fluid	Trouble Shooting	PEG/Tube Site
Family	Grand-mother	Provides care and support at home	Y	Y	Y	Y	Y
	Mother/Father	Provides care and support at home	Y	Y	Y	Y	Y
	Sibling(s)	Provides care and support at home including feeding Bolus	Y	Y	Y	Y	Y
Day Service	Manager + staff x 4+	Provides health and social care	Y	Y	Y	Y	Y
	Drivers of Transport x2	Collects and transports Client to and from Day Service. If feed is running they need to know how to respond to pump alarms	Y	N	N	Y	Y
Outside Care Agency	Carer to support at home 3+ staff	Provide all care and personal support to client and family at home	Y	Y	Y	Y	Y
District Nurses*	Nursing and Assessment x 2	Provide support to change Balloon Gastrostomy	Y	Y	Y	Y	Y
Respite	x6+ staff	As with family	Y	Y	Y	Y	Y
College	x4+ staff	Provide support with aspects of social care and feeding	Y	Y	Y	Y	N

*In other localities this role may be undertaken by a home enteral feeding company nurse.

"When her care package was put in place tube feeding was made such a big thing of.. Why? It shouldn't be a big issue, it's part and parcel of that person and staff should be trained. PEG training should be part of mandatory training for carers."
 (A parent). A sample training checklist for carers is shown in Table 2.

Table 2: Training Checklist for training carers

Area to be covered	When	By whom
<p>Pre-PEG education</p> <ul style="list-style-type: none"> • What is a PEG? • The procedure • Risks and benefits • Consent issues • Oral hygiene • Overview of aftercare of PEG • Regimens/admin of medication • Ongoing support networks and monitoring • Provision of feed and equipment 	<p>Start as soon as PEG is discussed as option.</p>	<p>Could be dietitian, nutrition nurse, SLT or most appropriate person from primary or secondary care. Could also utilise home enteral feeding company nurse.</p>
<p>Post-PEG education</p> <p>Care of the PEG tube –first 7-14 days then after site is healed. This will include:</p> <ul style="list-style-type: none"> • Flushing of tube • Care of the skin and stoma site • Oral hygiene • The feed regimen (bolus/ pump or combination) • Admin of medications • Supply of equipment and feed • Troubleshooting e.g., blocked tube, changing PEG ends etc, skin/ stoma problems, faulty equipment • Monitoring and ongoing support • Contact numbers 	<p>Start as part of pre-PEG education but go into more detail once PEG placed. Some aspects of care will be ongoing and part of the reassessment process during monitoring visits. It is important that whenever possible education is competency-based and appropriate to the carer's abilities and responsibilities with the client.</p>	<p>Depending on local provision the lead clinicians could be the nutrition nurse and dietitian. However the community nurse/home enteral feeding company nurse may take the lead.</p>

Issues to consider

Variations in practice can occur for a number of reasons. Carers are not a homogenous group and can be family members, friends, registered or non-registered staff. Where practicable, a multi-professional and multi-agency meeting would be of great advantage to reduce discrepancies in the implementation of enteral tube feeding practices (GPP). If this is not feasible during the in-patient phase then ideally it should be done as soon as possible after discharge.

This allows for as many key people to understand the rationale for the enteral tube feeding regimen; the impact on the client's quality of life; discuss their own roles and responsibilities and have the opportunity to express any concerns. However should there be local access to a dietitian specialising in LD, the client may already be known to their service and he/she needs to be part of the decision-making process pre-PEG. This will also enhance pre-planning and a seamless discharge home.

Where there is conflict to the implementation of recommendations and variances in practice by a carer/group of carers, it is recommended that the dietitian should document:

- The advice provided
- Relevant SLT assessments, videofluoroscopy findings including any documentation that supports the dietetic therapeutic recommendation(s)/intervention(s)
- Training given to reinforce practice as this may need to be revised

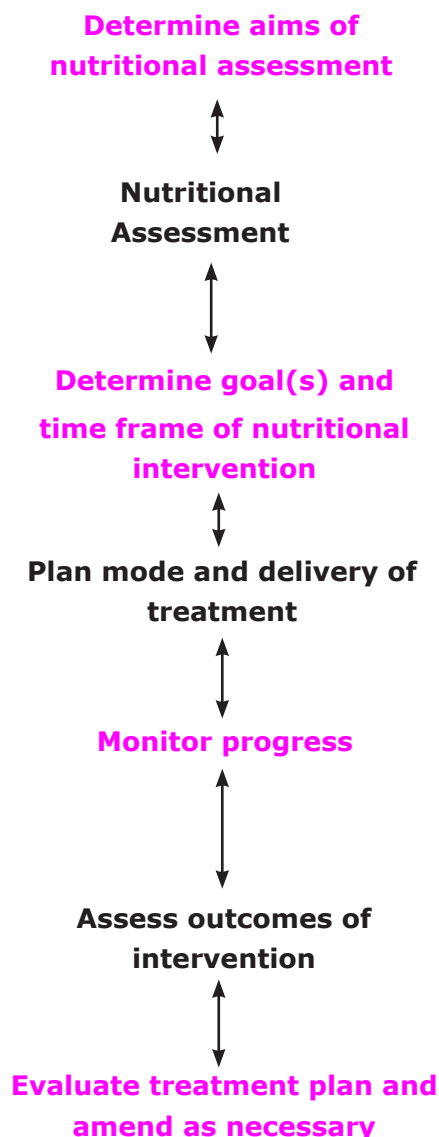
- Variations in practice as compared to the recommendations
- Expected consequences and concerns.

And should:

- Inform the wider MDT including GP and/or medical lead
- Call an MDT meeting to support resolving the conflict
- Seek clinical supervision.

Nutrition Assessment and Intervention

Figure 2. Assessment & Intervention Flow chart



3.2.1 Nutrition Assessment

Weight

It is accepted that weight is fundamental to assessing nutritional status, calculating requirements and monitoring intervention and progress. Specialist weighing equipment such as a ceiling track hoist with scales or wheelchair beam scales is needed to weigh people who are non ambulatory. It is important that scales are serviced and calibrated regularly. The posture of people with scoliosis needing special seating will change over time; those who receive intensive nutritional support may require more frequent re-assessment.

It is recommended to collaborate with the physiotherapist/occupational therapist to coordinate weighing of a new wheelchair on delivery (GPP).

Record if footplates, tray, headrest have been included in wheelchair weight and remove any bags from chair prior to weighing. This weight is then valid for subsequent weight checks, providing every aspect of the chair remains the same. Any alterations to the chair will need to be documented and require a new assessment of weight as changes invalidate previous assessments.

Figure 3. Client being weighed using wheelchair beam scales



Height

It is more difficult to measure an accurate height for people with physical anomalies. Alternative methods to estimate height include measuring ulna length, knee height and supine length following the natural curvature of the spine. All surrogate markers of height have been found to be inferior to self reported height (BAPEN, 2003).

Carers could be requested to measure a client's length using a standard (non-stretching) measuring tape in privacy and report back. However accuracy is not guaranteed and the resultant height can only be used as a guide. A small unpublished study by the authors compared estimated height using ulna length with measured height of 36 HETF adults with PMLD. Estimated height using ulna length was significantly different from height measured using a tape measure while the subject was lying on their side ($p < 0.001$).

Body Mass Index

The use of surrogate markers of height may affect the calculation of BMI and therefore classification of nutritional status (BAPEN, 2003). Clients may also have low bone density, altered body composition due to lack of weight bearing activity and developmental delay which are likely to affect calculation of height. The BMI of people with these conditions is lower than the standard reference ranges for health and exacerbate the degree of under-nutrition.

Taking into account the above, if BMI is used it is important to augment it with additional anthropometry to build up a picture of nutritional status (Stewart et al., 2006).

Mid Upper Arm Circumference (MUAC) and Triceps Skinfold (TSF)

In the general population, sequential measurements of MUAC and TSF are useful to monitor body composition and nutritional status in response to nutritional intervention, especially if weight is not available (Erdil, 2005). Unfortunately, it may not be possible to obtain repeatable, reliable, accurate and precise measurements for different reasons: the client may have upper limb muscle contractures, the non-dominant arm is not apparent, physical anomalies may mean that bony reference points are difficult to locate and the procedure may cause distress to the client.

Standard reference tables (Bishop et al. 1981) are based on an average American population who have a different body composition and stature to people with LD and physical impairments. The authors are not aware of any reference standards specific to this population to which the values can be compared. This is an area for future research.

Subjective Global Assessment (SGA)

Clients are assessed using subjective and non-specific parameters such as the ability to perform daily activities, checking subcutaneous fat stores, signs of muscle wasting, reported loose clothing, jewellery or dentures to rank them into one of three categories (Detsky et al., 1987). For guidance on SGA, refer to the Pocket Guide to Clinical Nutrition produced by the Parenteral and Enteral Nutrition Group (PENG) (Todorovic and Micklewright, 2007). In these instances such visual/clinical impressions should be recorded for example: "Appears normally nourished/over nourished/under nourished."

As with BMI, the presence of physical anomalies, low bone density due to lack of weight bearing activity, developmental delay and reduced mobility will impact on an individual's overall body composition. For example, a person who does not have any lower body or limb movement but is able to move their upper body and limbs will not have a uniform body composition. By looking just at their lower limbs they would be incorrectly classed as undernourished. It is important to assess whole body nutritional status.

3.2.2 Nutritional Requirements

The literature review did not reveal evidence to support specific nutrient requirements for the LD population. Nonetheless whilst there is a body of evidence (Dickerson et al 2003; Dickerson et al., 2002A; Dickerson et al.,1999; Gervasio et al 1997; Johnson et al., 1997) to indicate that people with severe neuro-developmental disabilities have lower energy needs, there is insufficient evidence to influence dietetic practice and this is an area for future research.

As with the general population, people with LD are vulnerable to nutritional deficiencies and related health consequences, for example Vitamin D deficiency and osteoporosis normally associated with institutional living (Fu Wong et al., 2006). However blood tests for vitamins and minerals can be unreliable and may not be representative of actual body stores. There is no substitute for a thorough assessment of intake and supplementation is recommended if intake (and, in the case of Vitamin D, exposure to sunlight) does not match requirements.

Energy

PENG (Todorovic and Micklewright, 2007) recommend using the Schofield Equation (Schofield, 1985). Knowledge of anthropometric, dietary history and ambulatory status will augment Schofield to determine energy needs and help prevent overestimation of requirements.

Standard equations and stress factors are an objective starting point to estimate energy and protein requirements. Ambulatory status is an important determinant of energy expenditure so it may be necessary to apply clinical judgment and be more conservative with energy supply for clients who are non-ambulatory (GPP). This has been demonstrated in local practice where a modest energy deficit of 50kcal a day in a non-ambulant client resulted in an unexpected 1.1 kg weight loss within the first month. Where clinical judgement is applied, monitoring using the appropriate parameters and frequency is even more important (GPP). Any changes made to energy intake should be modest due to dramatic impact on outcomes as highlighted above (GPP).

Johnson and colleagues studied the measured Total Energy Expenditure (TEE) by indirect calorimetry in 30 free living adults with cerebral palsy. TEE was highly variable between individuals and ambulation status was a significant predictor of TEE (Johnson et al., 1997).

A case study by Gervasio and colleagues showed that energy requirements were lower in a neurodevelopmentally disabled adult due to low body temperature (Gervasio et al., 1997). This was later confirmed by Dickerson and colleagues who studied six adults with severe neuro developmental disabilities with chronic hypothermia and PEG feeding. Indirect calorimetry measurements showed energy requirements were lower in clients with low body temperature (Dickerson et al., 2003). The authors also studied the effects of upper extremity posturing on measured Resting Energy Expenditure (REE) of non ambulatory tube fed adults with severe neuro-developmental disabilities. REE was 28% lower in those with contractures compared with those who had movement in upper extremities (Dickerson et al., 2002B). On the other hand the presence of trauma such as pressure damage can increase REE even in people with low body temperature (Liu et al., 1996).

Although small studies, they raise questions about the validity of prediction equations of assessment and calculation of requirements for people with PMLD. Actual energy provision may need to be markedly reduced as illustrated by the following case study from dietetic practice.

3.2.3 Case Study 3

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.

After a PEG was placed in 2003, she was advised to be Nil By Mouth (NBM) by the SLT and her health and epilepsy control subsequently improved and her weight was maintained on an enteral tube feed providing 400kcal per 24hrs.

Usual weight: 28-30kg.

Estimated height: 1.2m but considered unreliable to calculate BMI.

Aim of nutritional assessment

To determine current dietary adequacy and nutritional status to use as a baseline for future intervention.

Goals of nutritional intervention

Nutritional adequacy and improved seizure control.

Mode and delivery of treatment

PEG insertion and total nutritional support.

Figure 4: Nutritional requirements using Schofield Equation

Energy	
30 x 8.3 + 846 =	1095
Stress factor	0
10% DIT* and Activity	109
Total	1204 kcal

Protein requirements	
0.75g/ kg	23.0g

Fluid	
30-35ml/kg	900-1050ml

*Dietary Induced Thermogenesis

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.

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.

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.

3.2.4 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).

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. Readers are recommended to refer to *Administering Drugs via Enteral Feeding Tubes: A Practical Guide* and associated leaflets for patients, carers and general practitioners (BAPEN, 2004).

Table 3: Types of medications and effect on nutritional status

Class	Examples	Impact
Anticonvulsants/ Antiepileptics	Carbamazepine Phenytoin*	Impaired folate absorption. *Interacts with tube feed. Feed to be stopped 2hr pre and post dosage.
Antipsychotics/ Neuroleptics	Olanzapine, Risperidone, Haloperidol	Gastrointestinal disturbances, Rapid weight gain. Also affects integrity of swallow.
Anxiolytics	Diazepam, Lorazepam	Constipation, diarrhoea, increased salivation, vomiting
Antidepressants	Amitriptyline Fluoxetine*	Constipation, weight gain, decreased salivation. *changes in blood glucose
Antimuscarinics	Dicycloverine HCL Hyoscine	Constipation, vomiting
Hypnotics	Chloral Hydrate Temazepam	Gastric irritation
Mood stabilisers	Lithium	Weight gain, oedema
Osmotic laxatives	Movicol, Lactulose	Long term use can interfere with the absorption of fat-soluble vitamins.

Note: This list is intended as a guide and is not exhaustive

Post-PEG complications

Very few papers were found to support the premise that post-PEG complications are more common in clients with PMLD. Such complications include aspiration pneumonia, oesophageal reflux, chronic loose stools and tube misplacement (Castel et al., 2005; Flanagan and McAloon, 2003; Byard & Couper, 2001; DeVogelaere et al., 2000 and Lohiya et al., 2000). Clients who are NBM are more prone to bacterial overgrowth as lack of saliva and reduced swallowing has been shown to increase gastric pH (O’May et al., 2003), also gastric colonisation per se may increase risk of pneumonia in people who are already prone to chest infections (Heyland, 1998).

In practice clients with LD and severe scoliosis often receive long-term antibiotic therapy to counteract the debilitating effects of frequent chest infections due to aspiration. Lohiya and colleagues describe the use of fundoplication in an adult with PMLD who suffered antibiotic resistant aspiration pneumonia (Lohiya et al., 2000). Sub optimal oral hygiene resulting in increased pathogenic activity was cited for the continual aspiration.

Oral hygiene is a key component of the pre- and post-PEG training and education programme and emphasis on the impact on health needs to be fully understood by carers.

3.3 Monitoring

National guidance for monitoring tube feeding is produced by BAPEN (Todorovic and Micklewright, 2007; NICE, 2006; CREST, 2004). While these documents underpin the fundamentals of monitoring, this section aims to highlight the differences in health care needs influenced by the presence of LD and gives recommendations to ensure effective monitoring.

The client's nutritional status, degree of LD and other variables such as the impact of their environment, social situation and (as we have seen in Table 1) multiple carers at multiple venues will necessitate a different approach. The number of people involved can be as many as 60 including registered and non-registered carers, GP, psychiatrist, district nurses, LD and nutrition nurses and Allied Health Professionals (AHPs).

Monitoring should always include the client, as they may be able to articulate their views with support from a carer (GPP).

People with PMLD will be totally dependent upon carers to identify and recognise symptoms and problems, respond appropriately and report their progress. The sheer number and turnover of people involved in care makes monitoring, effective communication and dissemination of recommendations particularly challenging. Effective multidisciplinary and multiagency team working is essential for consistent good quality care.

3.3.1 Frequency of Monitoring

The aim of monitoring is to enable the client to achieve and maintain optimal health outcomes, reduce complications and unnecessary acute admissions (Erdil et al., 2005; Thomson et al., 2002; Schurink et al., 2001; Rabeneck et al., 1996).

NICE (2006) recommends HETF is monitored every three-to-six months, or more frequently if there is a change in condition. This necessitates the dietitian being informed of any changes in order to ascertain the appropriate frequency of monitoring. The dietitian may not be routinely informed of alterations in the client's clinical condition, health, wellbeing and social situation. Indeed the carers or family may be unaware of changes in health as the client may not be able to communicate these to them. Carers may not be aware of the significance of changes and therefore not communicate them.

For these reasons, the dietitian needs to be more vigilant and proactive in monitoring and reviews are likely to be needed more frequently than the general population. The frequency of monitoring is the decision of the managing dietitian on an individual client basis, tailored to meet their needs and determined by local standards.

It is recommended that monitoring is undertaken every three months (GPP).

3.3.2 What

A recommended list of parameters for monitoring is available (BAPEN Todorovic and Micklewright, 2007; NICE, 2006; CREST, 2004). See Appendix 4 for a sample checklist.

- **Weight:** Intensive monitoring of weight is important to prevent adverse weight gain especially in the early stages of enteral tube feeding. Weight monitoring can be used to evaluate intervention and thus enable adjustment of nutrient provision according to clinical need. People who need intensive nutritional support to improve nutritional status may require joint monitoring from the physiotherapist/occupational therapist for re-assessment. Depending on the client and circumstances at the time of nutritional assessment, plotting of sequential weights on a regular basis in conjunction with SGA may be the best that can be achieved (GPP).
- **BMI MUAC and TSF:** As discussed earlier (see Nutritional Assessment) these are rarely used with clients who have PMLD. If used, how often they are measured depends on individual clinical need and the usefulness in monitoring such indices.
- **Bowel function:** Enquiring about bowel function can lead to a plethora of non-standardised descriptions which mean different things to different people. Constipation is a frequent problem for people with LD and increases the risk of seizure activity (Thomas and Bishop, 2007; Dean, 2001) but it often goes unrecognised by carers because it is “normal” for the client. Contributing factors are poor gut motility, chronic inadequate fluid and fibre intake, chronic laxative usage, lack of physical activity and medication side effects. When enteral tube feeding is commenced, there is a risk of faecal impaction and vomiting despite adequate nutrition and fluid. Bowel function needs to be monitored to prevent complications. By providing adequate nutrition and fluid, the need for laxatives can be reduced. With regard to diarrhoea, this can occur due to a pre-existing bowel disorder, a side effect of medication, infection or too rapid a feed rate (CREST, 2004) and needs to be addressed as per local protocols. Diarrhoea may also be due to colonisation of helicobacter and, though experience indicates that people with LD are more prone to H-Pylori, there is no evidence to support this in the literature. By adopting a standardised way of describing bowel function there is less ambiguity and the standard of choice is the Bristol Stool Chart (Lewis and Heaton, 1997) (GPP).
- **Biochemistry:** Recommendations for monitoring biochemistry are given by BAPEN (Todorovic and Micklewright, 2007) and they apply to this population. As with any other treatment and intervention, taking blood for biochemistry should only be requested if there is a clinical need and clear benefit to the client. Venupuncture may present problems such as distress, challenging behaviour, the need for restraint and difficulty obtaining a sample due to poor venous access. NICE (2006) recommends biochemistry at least annually; however the MDT needs to assess risks versus the benefit to the client. If the client requires regular monitoring of anticonvulsant blood levels, it may be possible for both clinical needs to be addressed by one blood sampling session (GPP).

It is often the case that the dietitian is the only health professional to routinely monitor the client and for this reason it is considered good practice to check (by observation or questioning the carers) the stoma site and identify any training needs with the carer (**GPP**). This holistic approach can help to identify potential problems and is an opportunity to involve and empower the carer to adopt suitable aspects of monitoring.

3.3.3 Who

NICE (2006B) states that monitoring should be undertaken by the healthcare professional with relevant skills and training in nutritional support. The dietitian is best placed to lead but the profession practitioner carrying out the monitoring will vary across the country. In some cases monitoring may be delegated to competent support staff.

3.3.4 Where

Monitoring may be done wherever is most appropriate and could involve visits to see the client and carers at multiple venues. Face-to-face contact in the client's own home allows an invaluable assessment of how the client and their carers are coping with the feeding system and also provides reassurance and support (Brown, 2006; Madigan et al., 2002).

The greatest numbers of problems are reported within the first few days at home (Mensforth, 1999). Following discharge post-PEG insertion, a telephone call within one working day (of receipt of referral) and a domiciliary visit within five working days are recommended (GPP).

3.3.5 How

- Involve the client and carers in setting the goals of dietetic intervention and evaluation of progress.
- Discuss frequency of visits to help them understand the dietetic role, realise mutual expectations and agree level of support.
- Explain when to contact the dietitian or other Health Care Professional.
- Give emergency and routine contact numbers.
- Provide information about relevant aspects of enteral tube feeding, in the most appropriate format such as:
 - feeding regimen;
 - care of stoma;
 - correct use of equipment (NPSA, 2007);
 - skin integrity;
 - oral hygiene;
 - trouble shooting guide;
 - safe administering of medicines;
 - storage and method of supply of equipment and ancillaries.

And, finally, be prepared for the unexpected!

It is not uncommon to arrive at a visit with pre-determined aims and objectives, but leaving without achieving any of them. During the visit, the dietitian may be asked to assist in areas that are outside traditional dietetic practice, for example reading a letter written in English during a visit with an interpreter, or advocating for a move to healthier living conditions. Also, problems such as poor compliance to recommendations may become apparent and will need to be dealt with as a matter of immediacy.

Concerns may arise in relation to vulnerable people at risk from their environment. It is essential that the dietitian discusses any concerns with their line manager and follows protocols for the protection of vulnerable adults. This may not appear to be a role for the dietitian but by taking a holistic approach during a review and acting as a single point of access to the service, this eases the burden on the carers and helps reduce barriers. Such unresolved issues can have an indirect effect on optimising nutritional status.

On the other hand, unexpected improvements and progress may become apparent requiring aims and objectives to be reviewed.

One last point – do not underestimate the value of telephone contacts and being available.

"We feel involved in his nutrition and we keep a constant vigil on regurgitation. Feel we can ring anytime for advice or if concerned about anything, feel it's okay to ask the question. She's always there at the end of the phone." (Carers, 2008)

"I am totally involved. With me I was left to get on with it when it was done but knew the dietitian was there as support....my back-up if I get stuck." (A parent, 2008)

4.0 Training and Education

As previously stated, clients with LD have greater health needs than the general population and those requiring an enteral feeding tube are more likely to have complex health, physical, social and psychological needs. Specialist community services need to be in place to provide continuous support during the period of enteral tube feeding (Rouse et al., 2002).

4.1 Approach

Co-ordinated care from the multi-disciplinary team (NICE, 2006) is essential to ensure that correct and timely assessment, referral and pre and post enteral tube placement training and education happens (see Table 2). The multi-disciplinary team could consist of the:

- GP
- Dietitian
- Speech and language therapist
- Psychologist
- Community/LD nurse
- Community and hospital-based nutrition nurse specialist
- Pharmacist
- Consultant gastroenterologist
- Other health professionals who might need to be involved at various stages of the process.

In the event there is no provision for a multi-disciplinary team decision, then the lead clinician has to ensure that as many involved parties (both professional and informal) are consulted to ensure the decision to proceed to PEG placement is in the client's best interests and that all relevant aspects are covered and considered in the assessment process from which a management plan is formulated and agreed. A single clinician should not take sole responsibility for a PEG referral.

In order to achieve a co-ordinated approach several things need to be in place:

- A responsive specialised community service
- Good planning strategies
- Effective working partnerships between health, social and other agencies.
- Seamless transitions between primary and secondary care
- Good communication networks
- Shared referral criteria.

4.2 Needs of clients

As with any other group the following areas need to be carefully considered and the training needs for the clients identified (NICE 2006B). In this client group there is more emphasis required in certain areas as detailed below:

- Ethical, legal, consent issues – these can be particularly complex and require multi-disciplinary and multi-agency collaboration and if necessary advocacy should be explored.

- Potential risks and benefits for the client not the carer.
- Nutritional needs/indications for nutritional support.
- Options available i.e. oral/enteral/parenteral.
- Where and when to seek advice.

Hannon (2004) states that “better pre-admission assessment improves learning disabilities care”. This can also be applied to training and education for enteral tube feeding.

4.3 Pre-PEG assessment, training and education

Whilst there is an inconsistency of service provision countrywide, it is essential that people with LD and their carers, both formal and non-formal, receive adequate information pre-procedure to be able to make an informed choice and be able to be involved in the consent process. Such information needs to include the effect on the client’s health, psychological and social well being. Placement of an enteral feeding tube has a knock-on effect to many aspects of the client’s care such as:

- Timing of personal hygiene care
- Timing of therapeutic interventions e.g. physiotherapy, hydrotherapy, rebound
- Suitability of drug preparations*
- Timing of medications in relation to the feed*
- Transport to and from day centre/activities

* *With reference to White and Bradnam, 2007.*

It is important to be realistic about the impact enteral tube feeding can have on the family/carers as initially it could increase stress and heighten anxiety. This needs to be managed in a proactive and supportive way by the appropriate MDT member as ongoing support needs to be more than skin care and nutritional guidance (Sullivan et al., 2004).

“It was a case of information overload. There was a lot happening; we were in hospital and it was stressful. I went for the easiest option which was using a syringe as the pump was too much to take in at the time.” (A parent)

“We felt inadequate and wondered if we could do it for him.”
(A carer)

Remember that carers will have different levels of skills, knowledge and concerns, a one-size-fits-all approach will not meet everyone’s needs and aspirations. The pre-PEG assessment, carried out by a suitably experienced practitioner, will identify the training and educational needs of all those who will be involved in the management of the tube, feeding and medication regimens. In complex cases such as those involving clients with PMLD this ideally should include the consultant who is to place the tube. Prior knowledge of the specific tube type and client risks specific to the procedure will inform pre-placement training. Identified training and educational needs can then be addressed in the period of time leading up to the placement of the tube with post-procedure training continuing to ensure confidence and competency is achieved. Recognition of the family’s/carers’ contribution is essential and their needs also assessed and met. They can prove to be a valuable resource due to their in depth knowledge of the client and this should be utilised in the planning of all aspects of care.

4.4 Training and education areas to be covered

Training packages should be individualised for each client whilst being underpinned by a competency framework to ensure recognised standards of good practice are met and adhered to (GPP). The use of supporting literature in an accessible format (NICE 2006), is advisable to reinforce knowledge and used as an ongoing resource.

The training must be carried out by a competent practitioner with relevant experience who can observe practice. It is the legal duty of the carer's employer (which could be an agency or private provider) to ensure they access this training and are assessed within their own policies and protocols as competent. Client-specific training is required in situations where carers are non-registered. NICE (2006) states:

"Patients in the community having enteral tube feeding, and their carers, should receive training and information from members of the multidisciplinary team on:

- *The management of the tubes, delivering systems and the regimen, outlining all procedures related to setting up feeds, using feed pumps, the likely risks and methods for troubleshooting common problems and be provided with an instruction manual (and visual aids if appropriate).*
- *Safe administration of medications following locally agreed guidelines and risk assessment of individual clients.*
- *Both routine and emergency telephone numbers to contact a healthcare professional who understands the needs and potential problems of people on home enteral tube feeding.*
- *The delivery of equipment, ancillaries and feed with appropriate contact details for any homecare company involved."*

It is apparent, professionally and legally, that relatives and non registered carers can be educated in the management of enteral tube feeding which includes the provision of a prescribed feed and medication. The person who receives instruction is responsible for carrying out the task to the set standard. Suggested areas of training to be addressed are detailed in Appendix 5. Specific approaches and techniques need to be considered when clients display challenging behaviour and will form part of the multi-professional, multi-agency risk assessment.

4.5 Post-PEG/Enteral tube placement procedure

Following tube placement, ongoing training and support is vital particularly in the initial post procedure period and should be carried out by a competent practitioner.

"Felt like we were left to our own devices a bit. If I needed any help, someone would visit but would have appreciated a planned visit before the tube was placed so I knew someone was going to come and visit and check things were okay. Could have done with this in the first couple of weeks when you don't know if you are doing things correctly." (A parent)

"I'm a bit gung-ho – I will give it a go. Either she stayed in hospital longer or I got on with it. Looking back I needed more training...no input when I got home at all. I was shown once and then let loose." (A parent)

Once the client is established on the regimen, monitoring protocols need to be put into place as per local dietetic standards. Review of the training needs should be undertaken at least annually. However this may be more frequent if the client's situation changes e.g. alterations to a care package, residence or the enteral tube feeding/medication regimen (GPP).

5.0 Summary and Conclusion

Brown defines the specialist practitioner as one who consolidates and develops understanding of the health needs of a given population built upon a rigorous evidence base (Brown, 2001). In the absence of the latter, this Consensus Statement is a small step towards developing an understanding of the specific nutritional health needs of adults on home enteral tube feeding and who have LD.

At present, the level of the evidence base is that of best practice and the Good Practice Points are highlighted throughout the text as a guide for practitioners.

It is apparent from the lack of published data specific to this client group that further research is necessary in order for us to understand and respond to their needs and aspirations.

Recommended areas of research include:

- Is it possible to design and validate standard reference tables for clients with LD?

If the energy needs are reduced as shown by available evidence and clinical practice:

- Can this be expressed scientifically/mathematically to underpin meaningful assessment of nutritional status and nutritional requirements?
- Is this reduced energy need reflective of protein and other macro and micro nutrients? How can nitrogen balance be measured in clients who have PMLD?
- Are the rate of complications greater in clients with LD? Can this be stratified within sub-groups?
- Qualitative Research into QOL of clients with LD.

To name but a few, refer to Appendix 2 for unanswered key questions which would benefit from research.

The number of adults with LD on home enteral feeding is unknown but increasing as more children with complex needs and LD are surviving into adulthood and accessing adult services. Just over 2% of the population have LD but only 0.5% access service (DH, 2007B). These administrative norms are currently used in absence of demographic data to gain an estimation of the client base.

Sharing good practice is essential to move forward and could begin by the LD regional interest groups within the BDA MHG coming together to set an agenda for joint audit and research. With a relatively small client base as reflected by the number of available research papers, it would seem expedient for rigour to consider multi-centre audit and research projects both intra and inter-professional.

People who have LD present with a wide range of cognitive and physical abilities and wish to have access to services which have long been available to the non-disabled population in order to have an equitable quality of life (Learning Disability Advisory Group, 2001; Thompson and Pickering, 2001).

The skills challenge for any health professional is to provide – by observation and discussion – an evidence-based yet flexible and practicable intervention that includes and meets the aspirations and needs of each client. However, inclusion needs to be broader with the involvement of clients and their carers in service planning including audit and research as well as enabling individuals to make their own informed choices (DH, 2007B).

The National Health Services within the United Kingdom have a responsibility to commission mainstream services that, as well as specialist learning disability services, address the health inequalities of people who have LD.

In conclusion, maintaining long-term therapeutic interventions such as HETF for clients with LD is an increasing resource challenge for dietitians and nurses, whether in specialist teams or generic core services. Members of the LD specialist team have the flexibility to support, advise and in some cases undertake joint care with mainstream services, as well as provide a specialist service for those clients whose learning disability impacts significantly on their health and social care.

The formulation and adoption of this consensus statement is a small yet important step towards raising the profile of the nutritional needs of this client group, in particular those who are unable to enjoy satisfying their nutritional needs via the oral route.

*"It was disappointing to know that he needed a PEG as he **loved** his food, so the 'Mmmn' [lip smacking] factor had to go."* (A carer)

"It was just a top-up at first but over the years feeding was more difficult and she has learnt to live with it now – we all have." (A parent)

"Some things haven't improved as we used to enjoy eating out at restaurants. It's a shame he doesn't enjoy that anymore. But he is much happier now." (A parent)

6.0 Glossary

AHPs – Allied Health Professionals including dietitians, speech and language therapists, occupational therapists, physiotherapists, orthoptists, registered with the Health Professions Council (HPC).

BMI – Body mass index for relating a person's body weight to their height. The body mass index (BMI) is a person's weight in kilograms (kg) divided by their height in meters (m) squared.

Contractures – An abnormal, often permanent shortening, as of muscle or scar tissue, that results in distortion or deformity, especially of a joint of the body.

Dietary Induced Thermogenesis – The predicted rise in body temperature following ingestion of food.

Dual diagnosis – where a client has both mental health and LD. The mental health national service framework should be followed.

Fundoplication – Surgical intervention to relieve chronic reflux, often involves pinning the stomach much higher, thus reducing the likelihood of placing a device into the stomach as it may be pinned under the rib cage.

GPP – Good Practice Point. Based on a consensus of best practice.

Jejunostomy – A surgical procedure to create an opening through the abdominal wall (a "stoma") into the small intestine (the "jejunum"). Used for enteral feeding when it is necessary to bypass the upper gastrointestinal tract.

Kyphosis – Curving of the spine that causes a bowing of the back, which leads to a hunchback or slouching posture.

LRNI – Lower reference nutrient intake. This aims to define minimum nutrient requirements; this amount will only be sufficient for a small percentage of the standard population (about 2.5%) with low needs and will not be enough for most people. Individual intakes below the LRNI are likely to be inadequate.

MUAC – Mid-Upper Arm Circumference. Measurement of the non-dominant* arm midway between the shoulder and the elbow; can be used as a determinant of muscle mass.

*If right handed, the non dominant arm is the left arm. This is the gold standard used as defined by Bishop et al 1981.

PEG – A percutaneous endoscopic gastrostomy is an endoscopic procedure for placing a tube into the stomach through the abdominal wall. The procedure is performed in order to place a gastric feeding tube as a long-term means of providing nutrition to patients who cannot productively take food orally.

PMLD – Profound and multiple learning disabilities; that is, a person with more than one learning disability where their main learning disability is profound.

Re-feeding Syndromes – syndromes consisting of metabolic disturbances that occur as a result of reinstatement of nutrition to patients who are starved or severely malnourished.

RIG – A radiological inserted gastrostomy refers to a tube being inserted radiologically (opposed to an endoscopic procedure i.e. PEG). It is indicated for patients who have obstructing lesions in the upper GI tract, which prohibits the passage of an endoscope, or where tumour seeding is a risk. Sedation is required for clients who have LD even if they have poor respiratory function. Sedation is not generally required for the standard population.

RNI – Reference nutrient intake. The RNI is the amount of a nutrient that is enough to ensure that the needs of nearly all the group (97.5%) are being met. By definition, many within the group will need less. If an individual is consuming the RNI of a nutrient, they are unlikely to be deficient in that nutrient.

Scoliosis - A curvature of the spine, either congenital or acquired by very poor posture, disease or muscular weakness due to certain conditions such as cerebral palsy or muscular dystrophy.

SLT – Speech and language therapist; a specialist who evaluates and treats communication disorders and swallowing problems.

TSF – Triceps skinfold thickness. A measurement of subcutaneous fat taken by measuring skinfold thickness at specific sites including triceps, biceps, subscapular and iliac crest.

Vulnerable Adults – A person who is 18 years old or over, and who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him/herself, or unable to protect him/herself against significant harm or serious exploitation.

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Useful websites

BAPEN – www.bapen.org.uk

BDA MHG – www.dietitiansmentalhealthgroup.org.uk

Best Interest Guidance – www.bps.org.uk

Clear. For advice & training regarding making information accessible – www.clearforall.co.uk

Health indicators for people with learning disabilities – www.pomonaproject.org

Journal abbreviations – http://images.isiknowledge.com/help/WOS/O_abrvjt.html

Mental Capacity Act 2005 Short Reference Guide – www.bps.org.uk

PENG – www.peng.org.uk

RCN – www.rcn.org.uk

TalkingMats – www.talkingmats.com

EVIDENCE TABLE: Papers relating to Key Questions.

References in magenta have not been used in text

Key Question 1 : How informed consent is obtained.

There were no papers found in literature search relating to this question.

Key Question 2 : Complications specific to learning disabled clients receiving enteral feeding.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 2
Byard, R.W. & Couper, R.T.(2001).Acute gastric dilation and spastic quadriplegia. <i>J. Pediatrics.</i> 139 ,166	Case Report	Level 3	One individual with a LD- 20 year old male.	n/a – patient died.	Refers to complications with PEG feeding in patient with CP & LD.
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. <i>J Am Coll Nutr.</i> 18 , 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	Patients with severe neurodevelopmental disabilities have lower REE.
Dickerson, R.N., Brown, R.O.,(2005). Long term enteral nutrition support and the risk of dehydration. <i>Nutr Clin P.</i> 20 , 646-653	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	L D more at risk of dehydration if they are unable to communicate that they are dehydrated.
Flanagan, N.M. & McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. <i>Ulster Med J.</i> 72 , 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Lohiya, G-S., Tan-Figueroa, L. & Kuhler, H. (2000).Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? <i>J Intell Dev Disabil.</i> 25 , 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	In people with a LD, pneumonia is the leading cause of death due to aspiration.
Pitsinis, V. & Roberts, P. (2003) Gastrocolic fistula as a complication of percutaneous endoscopic gastrostomy. <i>Eur J Clin Nutr.</i> 57 , 876-878.	Case report	Level 3	One individual with severe learning & physical disabilities.	Advice re. reinsertion of PEG.	Rotation of stomach – type of complication which is associated more with LD.
Yarze, J.C. & Scalia, P.G. (1997) Feeding jejunostomy button replacement. <i>Gastrointest Endosc.</i> 46 , 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Refers to complications with PEG feeding in patients with CP & LD.

Key Question 3 : Exacerbation of gastric reflux.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 3
Castel, H., Tiengou, L-E. Besancon, I et al.(2005) What is the risk of nocturnal supine enteral nutrition? <i>Clin Nutr.</i> 24 , 1014-1018.	Prospective cross-over study (pilot)	Level 2-	Adults. 16 (6 with reflux)	GERD in mechanically ventilated	Positioning seems irrelevant to episodes of reflux.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000) Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? <i>J Intell Dev Disabil.</i> 25 , 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Fundoplication performed to reduce risk of reflux.

Key Question 4 : Other complications.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 4
Byard, R.W. & Couper, R.T.(2001) Acute gastric dilation and spastic quadriplegia. <i>J. Pediatrics.</i> 139 , 166.	Case Report	Level 3	One individual with a LD- 20 year old male.	n/a – patient died.	Acute gastric dilation/gastric gas bloat.
De Vogelaere, K., De Backer, A., Vandenas, Y. & Deconinck,P. (2000) Gastroileocutaneous Fistula: An unusual complication of percutaneous endoscopic gastrostomy. <i>Endoscopy.</i> 32 , S3-4.	Single case report	Level 3-	1 adult with LD and scoliosis	First Placement of PEG	4 months post insertion complications of misplacement occurred ie PEG had disappeared
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. <i>J. of Gastroen Hepatol.</i> 20 , 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Major & minor complications documented -comparable to other similar studies.

Flanagan, N.M. & McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. <i>Ulster Med J.</i> 72 , 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Heyland, D.K. (1998) Nutritional support in the critically ill patient. <i>Evid- Based Crit Care Med.</i> 14 , 423-440.	Systematic Review	Level 1-	Review of RCTs. Total of 58 papers met criteria.	TPN & EN in critically ill patients.	Paper states EN promotes gastric colonisation with potentially pathogenic bacteria & may ↑ risk of pneumonia – may be significant in LD clients who are already prone to chest infections.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000) Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? <i>J Intel De vDisabil.</i> 25 , 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Pneumonia as result of aspiration. Sub-optimal oral hygiene → ↑ in pathogens . ↑ gastric fluid retention - ? cause of continual aspiration.
McGrath, S.J., Splaingard, M.L., Alba, HM. et al.(1992) Survival and functional outcome of children with severe cerebral palsy following gastrostomy. <i>Arch Phys Med Rehab.</i> 73 , 133-137.	Retrospective and prospective case note	Level 2-	61. Children CP	PEG in long term care	Complications following procedure eg dumping.
O' May, G.A., Reynolds, N., Smith, A.R. et al (2003) Effect of pH and antibiotics on microbial overgrowth in the stomachs and duodena of patients undergoing percutaneous endoscopic gastrostomy feeding. <i>J Clin Microbiol.</i> 43 , 3059-3065.	Prospective case analysis	Level 2	(30) 20 – new and 10 undergoing PEG replacement	Gastric & duodenal aspirates post placement.	The effect of gastric pH on the composition of aspirate microbiotas – no oral intake leads to lack of saliva production & peristalsis and reduced swallowing increases gastric pH & reduces nitrite concentrations → microbial overgrowth.
Pitsinis, V. & Roberts, P. (2003) Gastrocolic fistula as a complication of percutaneous endoscopic gastrostomy. <i>Eur J Clin Nutr.</i> 57 , 876-878.	Case report	Level 3	One individual with severe learning & physical disabilities.	Advice re. reinsertion of PEG.	Notes minor & major complications & early & late complications which can arise in PEG feeding. Fistula between stomach & transverse colon.

Rabeneck,L.. Wray,N.P. and Petetrstone, N.J. (1996) Long term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. <i>J Gen Intl Med.</i> 11 , 287-293.	Retrospective cohort study	Level 2-	7369 PEG adults – analysis of case notes 1990 – 1992.	PEG	Complications such as aspiration pneumonia, as a result of procedure, abscesses and death.
Schurink, C.A.M., Tuynman,H., Scholten, P. et al (2001) Percutaneous endoscopic gastrostomy: complications and suggestions to avoid them. <i>Eur. J. Gastroenterol Hepatol.</i> 13 ,819-823.	Prospective cohort	Level 2+	Adults 263. Head & neck malignancies.	PEG	Prevention of complications depends on patient selection, procedure techniques and follow-up.
Yarze, J.C., Scalia, P.G. (1997) Feeding jejunostomy button replacement. <i>Gastrointestol Endosc.</i> 46 , 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Dislodgement of feeding tube & replacement by button.

Key Question 5 : Specific medication related issues

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 5
Clarke, D.M., Wahlqvist, M.L., Strauss, B.J.G. (1998) Undreating and undernutrition in old age: integrating bio-psychosocial aspects. <i>Age Ageing.</i> 27 , 527-534.	Review of prevalence studies	Level 1+	Review of 18 studies conducted in long term care facilities & acute hospitals.	Looks at physical & psychological factors leading to undernutrition. Suggestions on measures for screening.	Drugs causing taste & smell impairment would also apply to LD.
Dickerson, R.N., Brown, R.O.(2005) Long term enteral nutrition support and the risk of dehydration. <i>Nutr Clin P.</i> 20 , 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Carbamazepine lowers serum sodium level making it more difficult to interpret blood results.
Lohiya, G-S., Tan-Figueroa, L., Kuhler, H. (2000). Aspiration pneumonia and antibiotic resistant infections in a man with severe developmental disabilities: How much care is enough? <i>J Intel & Dev Disabil.</i> 25 , 83-89.	Case report	Level 3	One individual with severe physical & learning disabilities.	Fundoplication, antibiotics, tube replacement.	Antibiotic resistant bacteria – many antibiotics needed. Suggested drug therapy given.

O' May, G.A., Reynolds, N., Smith, A.R. et al (2003) Effect of pH and antibiotics on microbial overgrowth in the stomachs and duodena of patients undergoing percutaneous endoscopic gastrostomy feeding. <i>J. of Clin Microbiol.</i> 43 , 3059-3065.	Prospective case analysis	Level 2	(30) 20 – new and 10 undergoing PEG replacement	Gastric & duodenal aspirates post placement.	Staphylococci, E.Coli, & Candida spp. were isolated only from antibiotic treated patients.
Rodman, D.P., Stevenson, T.L., Ray, T.R. (1995) Phenytoin malabsorption after jejunostomy tube delivery. <i>Pharmacotherapy.</i> 15 , 801-805.	Case series	Level 3 -	1 subject – mental retardation, cerebral palsy, epilepsy, unilateral hemiplegia, jejunostomy.	Route of phenytoin administration changed to via jejunostomy following suspected aspiration pneumonia.	Consider bioavailability of medications especially anticonvulsants when choosing route of tube feeding as epilepsy is frequent diagnosis in LD patients. It is normal practice to allow 2 hours either side of phenytoin dose to improve bioavailability.
Zafonte R., Lombard, L., Elovic, E. (2004) Antispasticity medications – uses and limitations of therapy. <i>Am. J. Phys. Med. Rehabil.</i> 83 , S50-S58.	Review & analysis	Level 3	Comparisons of different drugs used for spasticity.	Oral versus IV .	Some medications used for spasticity would be given to clients with LD. Referring to route of administration i.e. oral route as opposed to IV.

Key Question 6 : Rate of complications v non-LD population

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 6
De Luis, D.A., Aller, R., de Luis, J. et al (2003) Clinical and biochemical characteristics of patients with home enteral nutrition in an area of Spain. <i>Eur J Clin Nutr.</i> 57 , 612-615.	Prospective observational study.	Level 2+	102 recruited over 3 yrs. 81 on oral nutritional support and 21 -tube fed. Pts. with head/ neck cancer, CVA/dementia, other tumours, anorexia, dysphagia.	Most were on oral nut. Support – only 21 tube fed.	Results show favourable outcome as so many were only on oral nut. support & made good recovery with regard to nutritional status. Those tube fed had lowest survival rate but also had poorest prognosis – not reflective of LD population on EN.

Key Question 7 : Benefits to clients

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 7
Flanagan, N.M. and McAloon, J. (2003) Gastric volvulus complicating cerebral palsy with kyphoscoliosis. <i>Ulster Med J.</i> 72 , 118-120.	Case report	Level 3-	1 young adult with CP	Case study of an 18 CP male with gastric volvulus a life threatening complication.	Successful novel use of PEG to extend life.
Kennedy M., McCrombie, L., Dawes, P et al., (1997) Nutritional support for patients with intellectual disability and nutrition/dysphagia disorders in community care. <i>J Intel Disabil Res.</i> 41 , 430-436.	Review of results of a 1986 paper	Level 4	Adults with intellectual disability; 318 inpatients and 99 community	Observation of nutritional status.	Under nutrition due to non-protein energy deficit. Improvements in QOL documented. Efforts to increase non-protein energy intake are required. Key point: Improvements in nutritional status may not reduce mortality rate of vulnerable patients with severe nutrition/dysphagia problems. Patients who can feed
McGrath, S.J., Splaingard, M.L., Alba, H.M. et al.(1992) Survival and functional outcome of children with severe cerebral palsy following gastrostomy. <i>Arch Phys Med Rehab.</i> 73 , 133-137.	Retrospective and prospective case note	Level 2-	61. Children CP	PEG in long term care	1 yr survival rates higher than adults and children who were mentally retarded. Decreased feeding time of 1.5hrs for carers perceived as good outcome
Rabeneck, L., Wray, N.P. & Petetrone, N.J. (1996) Long term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. <i>J Gen Int Med.</i> 11 , 287-293.	Retrospective cohort study	Level 2-	7369 PEG adults – analysis of case notes 1990 – 1992.	PEG	What are the benefits to survival., QOL? Need for ethical dimensions to be explored. One of the first papers looking at outcomes rather than just the safety issues of the procedure itself.
Rouse, L., Herrington, P. Assey, J. et al.(2002) Feeding problems, gastrstomy and families: a qualitative pilot study. <i>Brit J Learn Disabil.</i> 30 , 122-128.	Pilot Study	Level 3-	2 LD Adults with PEG. Interviews with professionals and parents	Qualitative analysis of interviews.	Need for early intervention re support for clients and carers. Better communication required.

Schurink, C.A.M., Tuynman, H., Scholten, P. et al. (2001) Percutaneous endoscopic gastrostomy: complications and suggestions to avoid them. <i>Eur J Gastroenterol Hepatol.</i> 13 , 819-823.	Prospective cohort	Level 2+	Adults 263. Head & neck malignancies.	PEG	Importance of follow up by nutrition team.
Sleigh, G. & Brocklehurst, P. (2004) Gastrostomy feeding in cerebral palsy: a systematic review. <i>Arch Dis Child.</i> 89 , 534-539.	Systematic review	Level 2++	25 papers	Gastrostomy/jejunostomy feeding in CP - Children	Lack of evidence to support assumption that G or J is a necessary, safe and effective treatment.
Thomson, M.A., Carver, A.D. & Sloan, R.L. (2002) Percutaneous endoscopic gastrostomy feeding in a district rehabilitation service. <i>Clin Rehab.</i> 16 , 215-220.	Retrospective case review	Level 2-	42. 16 - 64yrs	PEG for 6 years	Many patients deny severity of their swallowing which delays consent to PEG. Importance of follow up by Nutrition team.
Wendland, B.E., Greenwood, C.E., Weinber, I. & Young, K.W.H. (2003) Malnutrition in institutionalized seniors: the iatrogenic component. <i>J Am Geriatr Soc.</i> 51 , 85-90.	Retrospective case studies	Level 3	Adults. Elderly. 23 cognitively impaired	Analysis of food eaten	Individuals (in care) who are able to eat independently need 2000Kcal in order to achieve RDAs.

Key Question 8 : Benefits to Carers

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 8
Peterson, M.C., Kedia, S, Davies., P. et al. (2006) Eating and feeding are not the same: caregiver's perceptions of gastrostomy feeding for children with cerebral palsy. <i>Dev Med Child Neurol.</i> 48 , 713-717.	Controlled trial	Level 2+	26 caregivers of children	Examined perceptions of feeding and adherence to feeding recommendations for care givers	Negative response from 18 care givers when PEG was recommended. However 21 went on to report improvement once PEG commences. Useful for healthcare professionals in understanding carers concerns.

Rouse, L., Herrington, P. Assey., J et al.(2002) Feeding problems, gastrstomy and families: a qualitative pilot study. <i>Brit J Learn Disabil.</i> 30 , 122-128.	Pilot Study	Level 3-	2 LD Adults with PEG. Interviews with professionals and parents	Qualitative analysis of interviews.	Need for early intervention re support for clients and carers. Better communication required.
Sullivan, P.B., Juszezak,E., Bachlet, A.M.E. et al. (2004) Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. <i>Dev Med Child Neurol.</i> 46 , 796-800.	Prospective cohort	Level 2++	57 children with CP	Gastrostomy feeding	Improvements from baseline in QOL for carers. Ongoing support needs to be more than skin care and nutritional guidance.

Key Question 9 : Benefits to specific client groups within the LD population.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 9
Clarke, D.M., Wahlqvist, M.L. & Strauss, B.J. G. (1998) Undereating and under nutrition in old age: integrating bio-psychosocial aspects. <i>Age and Ageing.</i> 27 , 527-534.	Review of prevalence studies	Level 1+	Review of 18 studies conducted in long term care facilities & acute hospitals.	Looks at physical & psychological factors leading to undernutrition. Suggestions on measures for screening.	Could be applied to aging LD clients especially Down's syndrome.
Wendland, B.E., Greenwood,C.E., Weinber, I. & Young, K.W.H. (2003) Malnutrition in institutionalized seniors: the iatrogenic component. <i>J Am Geriatr Soc.</i> 51 , 85-90.	Retrospective case studies	Level 3	Adults. Elderly. 23 cognitively impaired	Analysis of food eaten	Individuals (in care) who are able to eat independently need 2000Kcal in order to achieve RDAs.

Key Question 10 : How benefit/burden ratio is assessed.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 10
Sullivan, P.B., Juszezak,E., Bachlet, A.M.E. et al. (2004) Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. <i>Dev Med Child Neurol.</i> 46 , 796-800.	Prospective cohort	Level 2++	57 children with CP	Gastrostomy feeding	Improvements from baseline in QOL for carers. Ongoing support needs to be more than skin care and nutritional guidance.

Key Question 11 : Choice of equipment used.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 11
Muramatsu,H., Koike,K. & Teramoto,A. (2002) Benefits of percutaneous endoscopic button gastrostomy in neurological rehabilitation therapy. <i>Inter J Rehab Res.</i> 25 , 157-161.	Cohort study	Level 2+	11 patients with severe stroke/ traumatic brain injury who were unable to swallow.	PEG button placed following period of N/G feeding & progress in rehabilitation observed.	PEG button inserted after complications arose from N/G feeding. Workers state PEG button better tolerated than conventional PEG in relation to activities in daily living.
Yarze, J.C., Scalia, P.G. (1997) Feeding jejunostomy button replacement. <i>Gastroenterol Endosc.</i> 46 , 191-192.	Letter	Level 4	One individual with a LD – 23 year old female.	Replacement of tube	Details specific tubes & techniques.

Key Question 12 : Choice of placement on enteral feeding tubes.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 12
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. <i>J Gastroenterol Hepatol.</i> 20 , 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Study supports finding by other workers that PEG feeding is preferable to N/G.

Muramatsu,H., Koike,K. & Teramoto, A. (2002) Benefits of percutaneous endoscopic button gastrostomy in neurological rehabilitation therapy. <i>Inter J Rehab Res.</i> 25 , 157-161.	Cohort study	Level 2+	11 patients with severe stroke/traumatic brain injury who were unable to swallow.	PEG button placed following period of N/G feeding & progress in rehabilitation observed.	PEG button enhanced quality of life & progress in rehabilitation, nutritional status & serum albumen.
Silas, A.M., Pearce, L.F., Lestina, L.S. et al (2005) Percutaneous radiologic gastrostomy : A comparison of indications, complications and outcomes in 370 patients. <i>Eur J Radiology</i> , 56 , 84-90.	Retrospective evaluation.	Level 2	370 patients – 177 gastrostomies endoscopically placed & 193 fluoroscopically by radiology.		Endoscopic & fluoroscopic gastrostomy tube placement safe & effective. More minor complications in PEG group could be attributed to lack of antibiotic therapy & routine antibiotics should be considered.
Taylor,H.M.(2002) Pneumonia frequencies with different enteral tube feeding access sites. <i>Am Assoc Mental Retardations.</i> 107 , 175-180.	Retrospective cohort	Level 2-	30 mixed tube feeds. 5 of these were JEJ 25 Gastrostomy	Incidence & frequency of pneumonia	They had statistically significant less episodes of pneumonia in the JEJ group. P=0.0014 Quality of the medical noted was commented on being poor.

Key Question 13 : How monitoring/evaluation is undertaken.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 13
Dickerson, R.N., Brown, R.O.,(2005) Long term enteral nutrition support and the risk of dehydration. <i>Nutr Clinl P.</i> 20 , 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Reinforces the importance of detection and prevention of dehydration using a range of subjective and laboratory measurements. Only some of the parameters recommended are readily available in the community and these are existing good practice. There is the opportunity to empower carers to detect the risks and signs of dehydration and respond appropriately.

Gervasio, J.M., Dickerson, R.N., Brown, R.O. et al (1997) Chronic hypothermia and energy expenditure in a neurodevelopmentally disabled patient : A case study. <i>Nutr Clin P.</i> 12 , 211-215	Case study	Level 3+	1 subject – profound mental retardation, spastic quadriplegia, NBM, gastrostomy with hypothermia.	Measurements of resting energy expenditure (REE) by direct calorimetry and gradual reduction of tube feed volume to prevent continued excessive weight gain.	Highlights the importance of close monitoring of nutritional status and frequent revisiting goals of nutritional support to prevent excessive weight gain.
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Key Question 14 : How nutritional status is assessed.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 14
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. <i>J Am Coll Nutr.</i> 18 , 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	REE measured & found to be significantly lower than predicted as estimated by Harris Benedict. Fat free mass best way of predicting REE. 2 equations developed which are more precise than conventional formulas.
Dickerson, R.N., Brown, R.O., Hanna, D.L. et al. (2003) Energy requirements of non-ambulatory tube-fed adult patients with cerebral palsy and chronic hypothermia. <i>Nutrition.</i> 19 , 741-746.	Case series	Level 3+	6 adults with severe neuro developmental disabilities & chronic hypothermia.	Indirect calorimetry measurements on PEG	Assessment of energy requirements lower in clients with low body temperature.
Dickerson, R.N. & Brown, R.O.(2005) Long term enteral nutrition support and the risk of dehydration. <i>Nutr Clin P.</i> 20 , 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Recommends assessment of hydration status using a range of subjective, objective and laboratory measurements to assess hydration status. Only some of the parameters recommended are readily available in the community and these are existing good practice.
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. <i>J Gastroenterol and Hepatol.</i> 20 , 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Range of anthropometric measurements recorded. MAC & TSFT considered preferable to other parameters of nutritional wasting in patients. Schofield formula used. Continuous feeding regime.

Liu, M.H., Spungen, A.M., Fink, L. et al (1996) Increased energy needs in patients with quadriplegia and pressure ulcers. <i>Adv Wound Care.</i> 9 , 41-45.	Pilot RCT	Level 2+	48 patients. 16 with quadriplegia and pressure ulcers, 16 with quadriplegia but no pressure ulcers and 16 healthy non-spinal cord injured subjects (control).	Resting energy expenditure (REE) in 16 individuals with quadriplegia and pressure ulcers compared with energy expenditure in 16 individuals with quadriplegia but no pressure ulcers.	REE measured by indirect calorimetry. REE higher in subjects with quadriplegia + pressure ulcers – requirement for increased caloric intake compared with subjects with no pressure ulcers – 23kcal/kg/day.
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Key Question 15 : How nutritional requirements are addressed.

Reference	Study Type	Evidence Level	Population and number	Intervention	Comments relating to key question No. 15
Dickerson, R.N., Brown, R.O., Gervasio, J.G. et al (1999) Measured energy expenditure of tube-fed patients with severe neurodevelopmental disabilities. <i>J Am Coll Nutr.</i> 18 , 61-68.	Prospective Study	Level 2++	20 :14 adults 6 children	Measurement of resting energy expenditure (REE) in non-ambulatory tube-fed patients with severe neurodevelopmental disabilities – found requirements were lower.	REE measured & found to be significantly lower than predicted as estimated by Harris Benedict. Fat free mass best way of predicting REE. 2 equations developed which are more precise than conventional formulas.
Dickerson R.N., Brown, R.O., Hanna, D.L. et al. (2002A) Effect of upper extremity posturing on measured resting energy expenditure of non ambulatory tube-fed adult patients with severe neurodevelopmental disabilities. <i>JPEN.</i> 26 , 278	Single Cohort	Level 2-	24	Resting energy expenditure (REE) P=<0.01	28% lower REE in those with contractures compared with those who had movement in upper extremities p=<0.01 <ul style="list-style-type: none"> • Small client study group • Uses Harris-Benedict equation Raises questions on validity of Nutritional assessment & calculating requirements with people with complex physical health needs

Dickerson, R.N., Brown, R.O., Hanna, D.L. et al (2002B) Validation of a new method for estimating resting energy expenditure of non-ambulatory tube-fed patients with severe neurodevelopmental disabilities. <i>Nutrition</i> . 18 , 578-582.	Single cohort	Level 2-	15 subjects – profound mental retardation, spastic quadriplegia, gastrostomy.	Measurement of resting energy expenditure (REE) by indirect calorimetry. Assessment and comparison of bias and precision of the Arlington Developmental Centre Equations and Harris Benedict Equation to estimate REE.	ADC-2 equation most suitable for predicting REE for adults with fixed contractures, but it still overestimated requirements but not as much as the Harris Benedict equation. ADC equations use skin folds to assess fat free mass but they and Harris Benedict are not used routinely in LD population. Study design not rigorous.
Dickerson, R.N., Brown, R.O., Hanna, D.L. et al. (2003) Energy requirements of non-ambulatory tube-fed adult patients with cerebral palsy and chronic hypothermia. <i>Nutrition</i> . 19 , 741-746.	Case series	Level 3+	6 adults with severe neuro developmental disabilities & chronic hypothermia.	Indirect calorimetry measurements on PEG	Assessment of energy requirements lower in clients with low body temperature.
Dickerson, R.N., Brown, R.O.,(2005) Long term enteral nutrition support and the risk of dehydration. <i>Nutr Clin P</i> . 20 , 646-653.	Case study	Level 3+	1 subject profound mental retardation, spastic quadriplegia, NBM, jejunostomy	Treatment of a patient with suspected fluid overload and subsequent dehydration.	Reinforces techniques to estimate fluid requirements.
Erdil,A., Saka,M., Ates,Y. et al. (2005) Enteral nutrition via percutaneous endoscopic gastrostomy and nutritional status of patients ; Five-year prospective study. <i>J Gastroenterol Hepatol</i> . 20 , 1002-1007.	Prospective study	Level 2+	85 patients – 22 female, 63 male (1 child), who had inadequate oral intake due to various underlying diseases.	PEG feed & observation of complications & effect on nutritional status.	Range of anthropometric measurements recorded. MAC & TSFT considered preferable to other parameters of nutritional wasting in patients. Schofield formula used. Continuous feeding regime.

<p>Fu Wong, S.T. et al. (2006) A survey of levels of Vit.D level in people with learning disabilities in a long stay hospital ward in Hong Kong. <i>J Intel Disabil.</i> 10, 47 -59.</p>	<p>Case series</p>	<p>Level 3</p>	<p>Population 122.</p>	<p>Measured of Vitamin D serum levels. Before & after the increase in tube feed volume.</p>	<p>Vitamin levels slightly better in tube fed clients but not significantly. Institutional lifestyle was reported to be a cause of low vit D. Reviewers comments: To many variables in diet. Normal., soft & Tube. Data lacking on anti-convulsant treatment. Highly reliant on old case notes & family self reporting questionnaire to clients sun exposure. Females had a lower level of Vit D.</p>
<p>Gervasio, J.M., Dickerson, R.N., Brown, R.O. et al (1997)Chronic hypothermia and energy expenditure in a neurodevelopmentally disabled patient : A case study. <i>Nutr Clin P.</i> 12, 211-215.</p>	<p>Case study</p>	<p>Level 3+</p>	<p>1 subject – profound mental retardation, spastic quadriplegia, NBM, gastrostomy withr hypothermia.</p>	<p>Measurements of resting energy expenditure (REE) by direct calorimetry and gradual reduction of tube feed volume to prevent continued excessive weight gain.</p>	<p>Assessment of energy requirements lower in clients with low body temperature.</p>
<p>Liu, M.H., Spungen, A.M., Fink, L. et al (1996) Increased energy needs in patients with quadriplegia and pressure ulcers. <i>Adv Wound Care.</i> 9, 41-45.</p>	<p>Pilot RCT</p>	<p>Level 2+</p>	<p>48 patients. 16 with quadriplegia and pressure ulcers, 16 with quadriplegia but no pressure ulcers and 16 healthy non-spinal cord injured subjects (control).</p>	<p>Resting energy expenditure (REE) in 16 individuals with quadriplegia and pressure ulcers compared with energy expenditure in 16 individuals with quadriplegia but no pressure ulcers.</p>	<p>REE measured by indirect calorimetry. REE higher in subjects with quadriplegia + pressure ulcers – requirement for increased caloric intake compared with subjects with no pressure ulcers – 23kcal/kg/day.</p>

Hierarchy and Quality Rating of evidence (Harbour and Miller, 2001).

- 1 Meta-analysis, systematic reviews, randomized controlled trials(RCTs).
 - 2 Systematic reviews of case control or cohort studies, case control or cohort studies.
 - 3 Non-analytical studies eg case reports, case series.
 - 4 Expert opinion.
- ++ Most/all methodological criteria met, low risk of bias.
 - + Some criteria met, high risk of bias
 - Few or no criteria met, high risk of bias.

In adults with LD who are fed via the enteral route is there evidence of:

1. How informed consent is obtained*
2. Complications specific to learning disabled clients receiving enteral feeding?
3. Exacerbation of gastric reflux *
4. Other complications*
5. Specific medication related issues
6. Rate of complications v non -LD population*
7. Benefits to the clients
8. Benefits to carers
9. Benefits to specific client groups within the LD population *
10. How benefit/burden ratio is assessed*
11. Choice of equipment used *
12. Choice of placement of Enteral feeding tubes
13. How monitoring/evaluation (follow-up) is undertaken
14. How nutritional status is assessed**
15. How nutritional requirements are addressed**

*** Specific recommendations for Adults with LD not found in literature review. These are areas for future research. However GPPs based on the clinical experiences of the LD practitioners within ETFiC4LD are to be found within the Statement.**

**** Energy only**

Core Members of a Specialist LD Team

- Dietitian
- Speech and language therapist – dysphagia
- Speech and language therapist – communication
- Clinical psychologist
- Consultant psychiatrist – epilepsy management
- Occupational therapist
- Physiotherapist
- LD community nurse – medication/epilepsy
- Social worker

Home Enteral Tube Feeding Monitoring Checklist

Parameter	Date	Date	Date	Date	Date	Date	Date
a Weight							
Reassess requirements if weight change							
b 5%							
c BMI							
d Mid arm circumference (MAC)							
e Triceps skinfold (TSF)							
f Oral intake							
g Oral hygiene							
h Appropriateness of current feed regimen							
i Feeding tube							
j Stoma site							
k General health and wellbeing							
l Medications							
m GI symptoms							
n Urine output							
o Bowel function							
p Skin integrity							
q Biochemistry							
r Supplies of feed, equipment and ancillaries							
s Training needs of the carers							
t Social situation							

Key tick = no problems NBM = nil by mouth S/N = see dietetic notes

Enter date of review in next available column from left to right. Under date, enter abbreviation from key for each parameter.

Essential Components of a Training Package

- Risks and benefits of procedure
- Tube placement procedures and specific risks
- Tube management (care of the stoma, tube, flushing etc)
- Regimen (bolus, pump or combination)
- Oral intake (as assessed by speech and language therapist)
- Use of pump
- Troubleshooting (basic skills to deal with common problems e.g. pump problems, tube blockage, sore skin etc.)
- How feed and equipment is obtained
- Contact details (who, when ,why)
- Support networks



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