

Best Practice Statement ~ *September 2007*

Caring for children and young people in the community receiving enteral tube feeding

NHS Quality Improvement Scotland is committed to equality and diversity. We have assessed this Best Practice Statement for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. For a summary of the equality and diversity impact assessment, please see our website (www.nhshealthquality.org). The full report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.

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ISBN 1-84404-471-8

First published September 2007

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Introduction

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHS Scotland.

The purpose of NHS QIS is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHS Scotland with advice, guidance and support on effective clinical practice and service improvements.

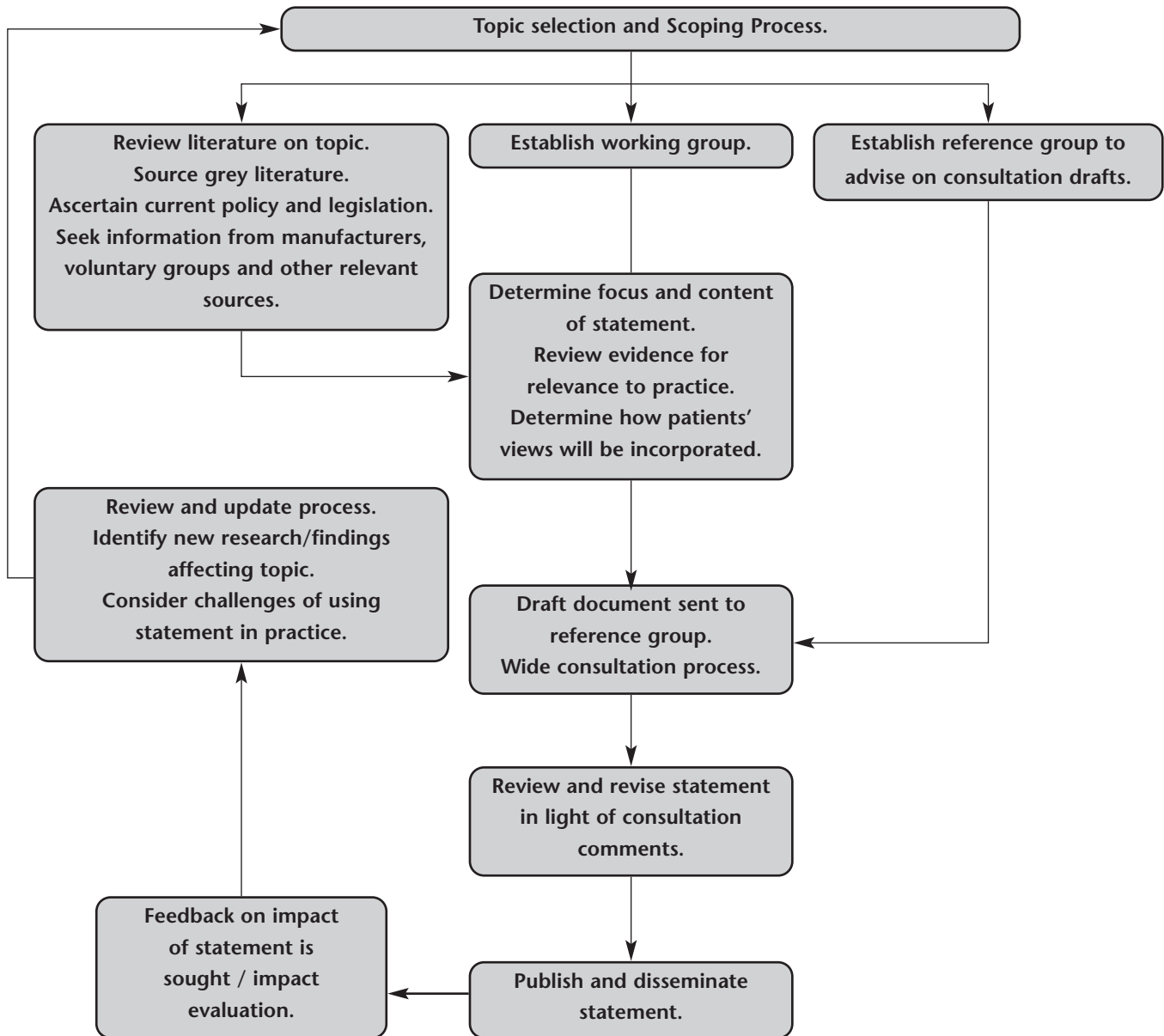
A series of best practice statements has been produced within the Practice Development Unit of NHS QIS, designed to offer guidance on best and achievable practice in a specific area of care. These statements reflect the current emphasis on delivering care that is patient-centred, cost-effective and fair. They reflect the commitment of NHS QIS to sharing local excellence at a national level.

Best practice statements are produced by a systematic process, outlined overleaf, and underpinned by a number of key principles:

- They are intended to guide practice and promote a consistent, cohesive and achievable approach to care. Their aims are realistic but challenging.
- They are primarily intended for use by registered nurses, midwives, allied health professionals, and the staff who support them.
- They are developed where variation in practice exists and seek to establish an agreed approach for practitioners.
- Responsibility for implementation of these statements rests at local level.

Best practice statements are reviewed, and, if necessary, updated after 3 years in order to ensure the statements continue to reflect current thinking with regard to best practice.

Key stages in the development of best practice statements



Best Practice Statement: Caring for children and young people in the community receiving enteral tube feeding

This best practice statement was originally developed in 2003 by the Community Children's Nursing Network supported by the Nursing and Midwifery Practice Development Unit. The aim of the statement is to offer guidance to nurses, allied health professionals, midwives, and health visitors on best practice relating to the care of children/young people in the community receiving enteral tube feeding. The statement was reviewed and updated in 2007 by a wider group including specialist nurses and dietitians. In addition to the review process, an audit tool has been developed to support practitioners/organisations wishing to audit their practice.

Tube feeding of children/young people being cared for in the community was identified as a priority by the Community Children's Nurse Network in consultation with their colleagues across Scotland. This statement refers to children and young people from birth until transition to adult services (this varies between areas but usually occurs between 14 and 19 years of age).

Some preterm/premature babies require care in medical neonatal units and may be discharged home, feeding via a nasogastric tube. For the majority, this is a temporary measure until full oral feeding is attained; for some babies their reliance on tube feedings may be more prolonged. Parents of these babies are taught how to pass a nasogastric tube and administer feeds in the neonatal unit.

Because a preterm/premature baby's physiology is different to that of an older baby, child or young person, and given the lack of robust research-based evidence specific to the preterm newborn, parents may be taught slightly different techniques to those described in this best practice statement. The differences include the fact that, in babies, flushing the tube with water before or after the feed and/or medications is not undertaken and air is not instilled into the tube for any reason.

Parents/carers should be reassured as to why there may be slight variations in the way in which a specific technique is taught. Differences in procedural technique and in professional opinion should not affect the level of support offered to parents/carers. Hospital-based neonatal nurses should ensure parents/carers understand that the techniques they have learned are suited to their baby and in-hospital care, but as the baby grows and is discharged home, these will change. Community practitioners may suggest adjustments to the parent's/carer's technique to fit with those suggested in the best practice statement, without causing distress to parents.

This statement specifically addresses issues in nasogastric, gastrostomy and jejunal feeding. The importance of communication and sharing of information between local and regional services is key to ensuring best practice for these children and young people and this is reflected throughout the statement. Child/young person-centred care, along with the need to involve and inform parents/carers, educational and social services in treatment is also highlighted in the statement. Children's information should be appropriate to their age and level of understanding.

The number of children/young people receiving tube feeding continues to grow annually. The annual British Artificial Nutrition Survey predicts that growth will continue as the clinical impact of improved nutritional status is recognised in a wider range of conditions. In February 2007, a snapshot exercise undertaken by working group members from every NHS Board in Scotland identified 194 children being fed via nasogastric tube, 717 children being fed by gastrostomy and 4 children being fed by jejunostomy.

The largest group of children receiving tube feeding in most areas of the UK are those with neurodisability. Research has found that almost all parents report a significant improvement in their child /young person's health and growth as a result of tube feeding and serious complications are rare¹.

Studies have demonstrated significant, measurable improvements in the quality of life of carers after insertion of gastrostomy feeding tubes². Carers usually report a significant reduction in feeding times, increased ease of drug administration, and reduced concern about their child/young person's nutritional status.

Some parents and carers experience considerable stress as a result of tube feeding. Factors such as the severity of the child/young person's illness/disability, constant caretaking demands and the level of support provided by the carers' social network all affect stress levels³. There is a need for greater practical and emotional support for families feeding children with severe disabilities^{4,5}.

Gastrostomy and nasogastric feeds can be given as bolus feeds, continuous feeding, or a combination of both. Jejunal feeds are always given by continuous infusion over several hours. The method chosen will be the one that best meets the needs of the child/young person⁶. Research by Townsley and Robinson⁷ highlighted some of the common problems experienced by children living in the community who require home enteral tube feeding. These included:

- a lack of information for families about how tube feeding would affect their child and the rest of the family
- difficulties co-ordinating the supply of feeds and equipment after discharge from hospital
- a lack of support for families to deal with problems arising from the care of the child /young person
- poor co-ordination of support services.

These research findings echo the inconsistencies and problems in practice raised by members of the Community Children's Nursing Network across Scotland. In order to explore the information needs of parents/carers of children/young people being tube fed NHS QIS commissioned a small-scale qualitative research study. The report from this study is available on the website (www.nhshealthquality.org). Key findings indicate that, while a range of tools is currently available, consistency of advice and training remains a concern. Reasons for differences in techniques taught, eg between hospital and the community need to be explained to parents/carers. The majority of parents /carers surveyed perceived the community children's nurse as their key source of advice, guidance and support. Parents/ carers vary in the amount of information they require as individuals but the better equipped they feel they are to deal with potential problems the more confident they appear to be in managing their child's feeding regimen.

Many NHS regions are trying to improve services by providing dedicated paediatric dietetic and nursing support. These workers are usually the key providers of advice and practical support for parents and carers. It is clear that the best care will be provided by experienced professionals who work closely in a multidisciplinary team, to develop hospital outreach services, co-operation with schools and liaison with social services⁸.



Section 1: Assessment and support of child/young person and parents/carers

Key issues :

- *Assessment, prior to feeding, followed by ongoing assessment of the child/young person and parents'/carers' ability to cope with tube feeding in the home setting is fundamental to the success and safety of the child/young person's treatment.*
- *Dietitians play a vital role in the assessment of nutritional status and nutritional requirements during this process.*
- *A key worker should be identified in the community to co-ordinate care and to be the first point of contact for families⁷.*
- *Risk assessment is essential prior to tube placement and should continue for the duration of feeding.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Prior to commencing enteral feeding, the child/young person receives a full nutritional, physical and developmental assessment. An assessment is also made of the parents'/carers' ability to undertake tube feeding at home.</p> <p>The child/young person/parents /carers are key in discussion and decisions relating to the child /young person's care</p>	<p>Assessment helps to establish that tube feeding is an appropriate treatment, and identifies the most beneficial method of administration for the child/young person.</p> <p>It is important to assess the parent/ carers attitudes/ability to learn how to tube feed and to assess any risks related to the home situation.</p> <p>Information and discussion promote understanding of reasons for commencing tube feeding and facilitates informed participation in decision making⁵. Oral feeding supports the development of oro-motor skills⁹.</p>	<p>There is evidence of a multi-disciplinary team approach in the assessment process and providing information and support to the child/young person/parent/carers in making the decision to commence tube feeding. Team members will include:</p> <ul style="list-style-type: none"> • paediatric nurse • paediatric dietitian • paediatrician <p>and, according to need, may include</p> <ul style="list-style-type: none"> • speech and language therapist • occupational therapist • physiotherapist • pharmacist • social worker • community health professionals <p>Local team members involved in each child/young person's care are identified in communication with the tertiary centre.</p> <p>Consistent, accurate information and support during decision making is given to the child/young person/parents/carers which includes all aspects of the practical, social and emotional management of tube feeding.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>The child/young person/parents/carers are given ongoing support to develop oral feeding skills where deemed safe to do so.</p>	<p>Encouraging parents to continue to help their child/young person enjoy the taste and feel of food can enable families to maintain the social and psychological bonds that mealtimes allow¹⁰.</p>	<p>There is evidence of multi disciplinary involvement in the ongoing assessment process and provision of information and practical support to the child/young person/parents/carers to encourage and promote oral feeding where deemed safe. This is extended to all carers and health professionals involved in the child /young person's care.</p> <p>There is documented evidence of when agreement has been reached that it is safe for the child/young person to commence oral feeding.</p>

Key challenges :

- *Ensuring a multidisciplinary approach to the care and assessment of the child/young person as recommended by the British Association of Parental and Enteral Nutrition¹¹.*
- *Providing effective communication strategies between Tertiary Centres, District General Hospitals and Community Staff.*
- *Ensuring that children's access to education is not limited by the need for tube feeding^{12,13}.*

Section 2: Planning and co-ordination of care prior to discharge from hospital

Key issues :

- *Tube feeding will usually be commenced in hospital. Continuous overnight feeding requires close supervision and should be commenced in hospital with the exception of palliative care.*
- *The child/young person and family are active partners in decisions related to care and treatment choices.*
- *A dietitian will advise the health care team regarding the agreed feeding plan, following discussions with the family and healthcare team. The dietitian will provide information regarding the proportion of the child/young person's nutritional requirements that are met by the tube feed and plan any further increments.*
- *The child/young person's key worker in hospital co-ordinates support for families in hospital and discharge arrangements and will help identify person for tube changes if family member not trained.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>The child/young person/parents/ carers understand the need for tube feeding and have undertaken a training programme and safely demonstrated the procedures taught to them.</p>	<p>To promote safety for the child/young person and the family</p> <p>To ensure that the child/young person/parents/carers can demonstrate safe tube feeding techniques and can recognise problems if they arise and know what action to take.</p>	<p>The education of parents/carers begins on the ward as an integral part of the discharge planning process.</p> <p>Documentation eg a training checklist should be sent to the receiving hospital/community nurse at the point of discharge</p> <p>The child/young person's named/allocated nurse in hospital is responsible for co-ordinating the appropriate education of parents/carers. This may include the following procedures (depending on route of feeding):</p> <ul style="list-style-type: none"> • passing and caring for their child /young person's nasogastric tube • administering tube feeds • caring for their child /young person's gastrostomy or jejunostomy tube • preparation and storage of feed • pump training • cleaning of equipment

Statement	Reasons for statement	How to demonstrate statement is being achieved
		<p>A home visit by community staff (eg health visitor, community children’s nurse, nutrition nurse specialist) takes place to support parent/carer in providing a suitable environment for tube feeding prior to tube being inserted (eg storage space, infection control issues).</p> <p>Parents/carers carry out procedures under the supervision of nursing staff initially*. This may be recorded on a training checklist as appropriate (Appendix 6).</p> <p>Verbal information is always supported by written guidelines (eg Appendices 1-4). Parents/carers are aware of what to do if the tube falls out.</p> <p>The child/young person’s named/allocated nurse in hospital is responsible for informing all community staff involved with the family of the details of the child/young person’s discharge.</p>

* Individuals will vary in the amount of time and supervision required before they can demonstrate safe practice. It is not possible to specify the number of times an individual should observe or practice techniques. A supportive relationship that allows parents/carers to learn the skills needed to care for their child and to seek practical advice is key to building confidence.

Key challenges :

- *Ensuring that the discharge planning process is ongoing from the date of admission until discharge if children are admitted to hospital.*
- *Developing a mechanism to allow feedback between the hospital and community to facilitate smoother transfer between services, eg involving the key community worker in the educational process⁴.*
- *Providing a care plan for use by all community professionals which includes the child/young person’s feeding regimen (including tube feeds and oral intake) and individual patient needs⁷*
- *Ensuring that parents/carers/child/young person are involved in any decisions requiring changes to care plan.*
- *Ensuring that information is available for families whose first language is not English or for individuals who may have difficulty with written information.*

Section 3: Equipment and supplies

Key issues :

- *Equipment is chosen that is best suited to the needs of the child/young person.*
- *Selection of equipment and supplies is dependant on local policy and reflects the knowledge, skills and understanding of professionals in specific geographic areas.*
- *Dietitians are key to the process of sharing information and liaising with the child/young person's GP and feed/equipment suppliers.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>The child/young person requiring tube feeding in the community receives all the necessary equipment and supplies.</p>	<p>Difficulties in obtaining necessary supplies in the community have been highlighted^{7,15}.</p>	<p>Parents/carers know how, when and where to obtain supplies.</p> <p>The individual responsible for ordering supplies for the child/young person in the community is identified and a referral made before discharge.</p> <p>Information is shared between the multi-disciplinary team caring for the child/young person in the community eg community children's nurse, paediatric dietitian, health visitor, GP, community paediatrician, school nurse.</p> <p>The child/young person's key worker and/or paediatric dietitian in hospital provide community staff with information on the feed type, amount, method of administration, feeding regimen and equipment required, including the type of container. There is evidence that this information is documented for future reference.</p> <p>The GP is contacted prior to discharge to prescribe the appropriate feed.</p> <p>Information is available on local supplies system.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
		<p>On discharge from hospital the child/young person is provided with an initial 7-day supply by the hospital to last until the first home delivery.</p> <p>Parents/carers are aware of the systems in place for home delivery or collection of supplies. They are provided with a contact telephone number for use in case of equipment failure.</p> <p>Parents/carers are aware of guidance relating to items marked "single use" and "single patient use"¹⁶ and how to clean/maintain reusable equipment.</p> <p>Parents/carers have written information on how to dispose of clinical waste safely. This will depend on local policy.</p>

Key challenges :

- *Utilising standardised pro-forma to facilitate sharing of information relating to equipment and supplies between the centre initiating tube feeding and staff caring for the child/young person in the community.*
- *Liaising with suppliers to ensure provision of equipment and supplies coincides with child/young person's discharge home.*

Section 4: Care of the gastrostomy/jejunostomy site and tube

Key issue :

- *Skin care around the gastrostomy/ jejunostomy site aims to prevent infection, excoriation and breakdown. This is best achieved by keeping the area clean and dry¹⁷.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
The child/young person receives hygiene to the area surrounding the gastrostomy/ jejunostomy tube.	To maintain healthy skin surrounding the gastrostomy/ jejunostomy tube in order to prevent infection and overgranulation.	<p>There is documented evidence that parents/carers have received information relating to the procedure for maintaining healthy skin.</p> <p>Each family is provided with guidelines to follow relating to infection. This includes information on:</p> <ul style="list-style-type: none"> • how to prevent an infection • how to identify signs of infection • appropriate action to take in response to signs of infection.
Any potential problems with the tube and surrounding area are recognised, enabling relevant and appropriate action to be taken.	To maintain integrity of the tube.	There is documented evidence that parents/carers are aware of the problems that may occur with their child's gastrostomy/ jejunostomy tube and know what action to take if problems do arise (Appendices 2 - 3).

Key challenges :

- *Ensuring that all parents/carers and other relevant individuals in the community are aware of action plan and what to do in case of the tube coming out.*
- *Ensuring health professionals are aware of importance of time scales if tube needs replacing. Tube replacement is more likely to be successful if carried out within 2 hours.*

Section 5: Oral Care

Key issue :

- *Maintaining a moist and healthy mouth is important in the care and comfort of children receiving tube feeding.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
Child/young person receives oral care.	Children who receive reduced or no oral feeds require moisture to prevent their mouth becoming dry ¹⁸ .	There is evidence that parents/carers have been instructed on the most efficient way of providing oral hygiene depending on the child/young person's individual needs.
	Tooth brushing is important to remove plaque. Dental caries cause pain and infection as well as aesthetic problems and loss of function ¹⁹ .	The child/young person has adequate equipment to carry out oral hygiene, ie toothbrush, toothpaste, mouthwash (if appropriate). Children are registered with a dentist and attend for assessment and thereafter up to 4 times a year for intensive preventative treatment, according to the dental risk assessment ^{19,20} .

Section 6: Tube feeding at school

Key issue :

- *The school health services are involved in discussion with teachers, parents/carers and the child/young person regarding the child/young person's needs at school.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>The child/young person receives tube feeds at school if needed.</p>	<p>To promote inclusion of the child/young person within the school environment and avoid disruption to the child/young person's routine²¹.</p>	<p>The child/young person has a School Health Care Plan¹³, which includes guidelines for administering the feeds.</p> <p>School staff receive appropriate training and assessment before undertaking any procedures (the person providing the training may vary between areas). Training includes information on:</p> <ul style="list-style-type: none"> • use and care of the child/young person's tube • storage of feed • cleaning of equipment • infection control • risk assessment • activity levels of child/young person. <p>Guidelines are provided regarding what to do if the child/young person's tube falls out and needs to be replaced.</p> <p>Systems are established for the delivery of supplies and equipment necessary for feeding to the child /young person's school. Parents may be required to provide equipment and feed.</p>

Key challenges :

- *Local guidelines address the issue of who provides training to school staff: procedures will vary between areas.*
- *Ensuring that training extends to staff in wider social care settings, emphasising inter-agency and cross-boundary working in the care of children with complex needs.*
- *Ensuring that there are sufficient resources to enable children to be tube fed during the school day.*

Section 7: Follow-up care for the child/young person receiving tube feeding

Key issues :

- *Children receiving tube feeding should be followed-up regularly, according to need^{8,22} by members of the multidisciplinary team (including paediatrician, paediatric dietitian, nursing staff). Guidance for good practice is provided in Appendix 5.*
- *Professionals should monitor the practical, social and emotional impact of the child/young person's tube feeding on the family as a whole⁷.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
Children need regular review of their care by eg the community children's nurse, paediatric dietitian, speech and language therapist and paediatrician. Frequency of review will be determined by age, condition or complications (Appendix 5).	The child/young person's needs vary depending on their age and underlying medical needs.	Follow-up includes assessment of the child/young person's weight, height/length, head circumference (infants), route of feeding, oral intake, feed type, feeding regimen, equipment and supplies. There is documented evidence of a long-term plan for children receiving tube feeding.
Accurate anthropometric monitoring is essential.	Health professionals should be able to accurately monitor growth and development. To ensure optimal growth and nutritional status.	The feeding plan should be modified regularly to optimise growth whilst avoiding excessive weight gain. Parents/carers are aware of who to contact with feeding-related problems. Weight and height/length and body mass index (BMI) are measured on a regular basis* using age appropriate equipment and techniques ²³ . Growth parameters are recorded in the child/young person's centile chart.**

* Intervals at which the child/young person is weighed will depend on the age and condition of the child/young person. This may be as frequently as weekly for young infants to 3-6 monthly for older children.

** Where possible, health professionals should aim to use one set of equipment for all measurements.

Key challenges :

- *Ensuring child/young person/parents/carers have access to a named paediatric dietitian.*
- *Ensuring staff are trained in obtaining growth parameters and plotting centile charts appropriately.*
- *Ensuring the smooth transition of care to adult services for children at the age of transition.*

Glossary

anthropometrics	The measurement of growth.
aspiration	Taking a sample of gastric contents for pH testing.
balloon	A water filled balloon holds some gastrostomy tubes securely in the stomach.
balloon port	Valve on gastrostomy tube to insert water into balloon.
body mass index (BMI)	Weight (in kilograms) divided by height (in metres). Used as a measure of nutritional status in conjunction with a BMI centile chart for children.
bolus feeding	A measured amount of feed that is given slowly by syringe (gravity) over 15-20 minutes or via a feeding pump over a set time period.
centile chart	Used to assess an infant/child's physical development. The lines of growth on the chart are called centiles. The number of the centile (from one to a hundred) predicts the percentage of infants/children who are below that measurement for a particular age eg, if a baby falls within the 10th centile, it means 10% of all babies will be smaller and 90% will be bigger. A baby would be expected to follow the centile if displaying a 'normal' growth trend.
clinical waste	Used medical equipment for disposal.
continuous feeding	A volume of feed delivered by a feeding pump at a constant rate over a period of time.
decanting	Pouring feed from the original container into the giving set container.
dysmotility	When muscles in the gastrointestinal tract (oesophagus, stomach, small and large intestines) are not working normally.
endoscope	An instrument used to obtain a view of the interior of the gastrointestinal tract.
external fixator	A device that holds the gastrostomy tube in place against the skin.
fundoplication	A surgical operation for treatment of gastro-oesophageal reflux.

gastric contents	Stomach contents.
gastro-oesophageal reflux	The backward flow of stomach contents from the stomach into the oesophagus (food pipe).
gastrostomy tube	A feeding tube that is inserted surgically into the stomach. This allows liquid feed / fluids / medicines to be delivered directly into the stomach.
giving set	Plastic tubing that delivers the feed.
Home Enteral Nutrition (HEN)	The provision of enteral tube feeding to children at home.
hydrocolloid dressing	A type of highly absorbent wound dressing.
jejunal feeding	Introducing liquid feed, using a special soft tube, directly into the jejunum (part of the small intestine). May be directly into jejunum (as below) or via a gastric port.
jejunostomy	A surgical procedure that creates a special opening (stoma) to allow artificial feeding via the jejunum.
nasogastric tube	A narrow tube that is passed into the nose and down the oesophagus (food pipe) into the stomach, which allows liquid feed to be delivered directly into the stomach.
oral feeding	Food and drink taken by mouth.
percutaneous endoscopic gastrostomy (PEG)	A procedure performed under anaesthetic to insert gastrostomy tube.
pH indicator paper or strip	Paper or strip that measures the amount of acid in stomach contents.
post-pyloric feeding	Where liquid feed is introduced into the part of the intestine immediately following the stomach.
single use	Use once only and the discard.
single patient use	Can be used more than once on one patient only.
skin level gastrostomy tube	Tube that lies flush against the skin; an inflatable balloon at one end of the tube keeps the tube in place in the stomach.
stoma	A surgically created opening into the body from outside.

Appendices

It is recognised that many good examples of information relating to tube feeding in children/young people have been developed at local level.

The following appendices provide guidelines that could be adapted for use by the child/young person/parent/carers and by professionals.

The information contained in the appendices incorporates knowledge gained from written evidence and from the consensus of the working group.

Guidelines from NHS Board areas across Scotland were reviewed by the working party. Information from guidelines produced by the Royal Hospital for Sick Children, Edinburgh and Tayside Dietitians' Network is included within the appendices.

Appendix 1: Passing and caring for the child/young person's nasogastric tube

Short-term tubes are made of polyvinylchloride (PVC) and can remain in place for between 3-10 days. Manufacturer's guidelines should be used to determine the length of time a tube can be left in place. If a tube is accidentally removed prematurely a new tube should be used. "Single use" is usually recommended.

Long-term tubes are made of polyurethane and have a wire to aid passing the tube. The wire is removed once the tube has been passed but should be kept in a safe place in case the tube has to be re-passed. The manufacturer will provide guidance regarding the length of time the tube can remain in place, cleaning and storage of the tube.

Passing the nasogastric tube

- wash your hands before and after the procedure
- collect equipment (nasogastric tube, 50mls syringe, pH indicator paper or strip, water to flush, tape to secure, glass of water/juice if appropriate)
- explain to the child/young person that you are going to pass the nasogastric tube
- babies can be wrapped in a blanket or towel to help keep them secure and laid flat on their back (unless another adult is available to assist holding the child); older children may prefer to sit up with their head tilted slightly forward
- determine length of tube to be inserted by measuring the tip of the tube from nose to ear and then measure from ear to stomach²⁴; note the mark on the tube or keep your fingers on the point measured
- ensure end cap is firmly in place on the end of the tube, to prevent leakage of gastric contents
- select nostril that is clear, where possible alternate the nostril being used
- lubricate tip of the tube using a water based solution and/or follow manufacturer's guidelines
- insert tip of tube into nostril and slide backwards along the floor of the nose
- if there is any obstruction, pull tube back and turn it slightly and advance again. If obstruction is felt again try the other nostril
- as the tube passes to the back of the nose, advise child/young person to take sips of water (if appropriate) to help the tube go down or in the case of a baby offer them a dummy if they have one.

If at any time the child/young person starts coughing or their colour changes stop the procedure immediately and remove the tube

- advance the tube until you reach the point where the tube was measured
- secure the tube in position using a barrier product such as hydrocolloid dressings to protect the skin and transparent films
- the position of the tube should be confirmed after passing it and prior to using it for administering any feed or medications.

Checking the position of a nasogastric tube²⁵⁻²⁷

- wash your hands before and after the procedure
- explain to the child/young person that you are going to check their tube
- remove the end cap from the tube
- attach a 50ml syringe to the end of the tube unless contraindicated by manufacturer's instructions^{24,28}.
- aspirate gastric contents from the child/young person's stomach by gently pulling back on the plunger until a small amount of fluid appears in the syringe
- detach the syringe from the tube remembering to replace the end cap of the tube
- test the pH of the fluid using pH indicator paper or strip. The indicator paper or strip should change colour to read a pH of 5.5 or less.

If it is difficult to obtain aspirate:

- attempt to push the tube's port away from the stomach wall. Insert 3-5ml of air via syringe, down the nasogastric tube. Try again to aspirate the tube and test with pH indicator paper or strip
- lie the child/young person on their left side and then retry aspirating the tube
- ask the child/young person to take a small drink, if allowed, then try to aspirate the tube
- try advancing or pulling the tube back slightly
- if unsure if the tube is correctly positioned, remove and re-pass the tube or seek further advice from community or hospital professionals
- once the tube is in the correct position, if using a long-term tube remove the guide wire and close the port
- flush the tube with recommended amount of cooled boiled water.

Appendix 2: Caring for gastrostomy tubes

Skin care for percutaneous endoscopic gastrostomy (PEG) tube, Two main types of PEG tube are commonly used - Freka and Merck. Care of the tube may vary according to the type of tube. Manufacturer's guidelines and local policy should be referred to.

Always wash and dry hands before touching the tube

Immediate post operative care - refer to local policy

- leave external fixation device in place until advised to loosen
- clean skin around stoma site and under retention device with sterile water using gauze and ensure the skin is then dried thoroughly
- avoid using creams and talcum powder as they can irritate the skin and cause infection. Creams can reduce the effectiveness of the retention device and can damage the tube material.
- avoid occlusive dressings as they may promote excess moisture
- immersion baths should be avoided to allow the tract to form and avoid infection.

Ongoing care

- if the child/young person has a PEG tube that falls out, medical attention must be sought **as soon as possible**
- note the position of the external fixator device so that it can be returned to the same point on the tube after cleaning. Loosen the external fixator device as directed by the manufacturer's guidelines, to enable thorough cleaning of the skin around the stoma site
- clean the site with water and dry thoroughly
- retighten the external fixator so that it lies approximately 2mm from the skin surface, this may need to be loosened or tightened as the child / young person's weight alters
- loosen the external fixator and push the tube in a little way and turn tube 360° on a daily basis and then pull tube back to original place (this depends on tube manufacturer's guidelines and local policy)
- if rotation causes pain or tube will not turn, stop and contact healthcare professional for advice
- inspect the skin for signs of redness, swelling, irritation, skin breakdown and leakage
- the need for a dressing will depend on the child/young person's skin condition and will require individual assessment.

Balloon retaining gastrostomy tubes

Checking balloon inflation

This should be done on a weekly basis

- wash hands before and after the procedure
- attach a syringe onto the valve of the balloon gastrostomy
- it is advisable to hold on to the tube, ensuring it remains in the child/young person's stomach
- gently draw back the plunger on the syringe until no more water comes out of the internal balloon
- check the recommended volume of the balloon as stated by the manufacturer
- using cooled boiled water, reinsert recommended volume through the valve to re-inflate balloon.

Replacing tube

- if a gastrostomy tube falls out then it should be replaced as soon as possible, preferably within 1-2 hours, or the stoma will start to close
- parents/carers should be aware of who to contact or where to go if tube falls out
- the procedure for changing the gastrostomy tube will depend on each individual manufacturer's guidelines
- guidelines for the frequency of changing tubes should be provided by the manufacturer
- staff / parents and carers involved in changing gastrostomy tubes should have received appropriate training
- a replacement tube should be kept with the child/young person (eg at school).

Care of balloon gastrostomy

- keep skin clean and dry
- turn tube 360° on a daily basis
- flush with cool boiled water through feeding set before and after feeding, and in between medications
- clean feeding sets after each feed and replace after 2 weeks
- replace balloon gastrostomy as per local hospital policy.

Appendix 3: Caring for the child/young person receiving jejunal feeding

The use of jejunal or postpyloric feeding, where feed is delivered directly into the small intestine, is gradually on the increase in particular for a child/young person with worsening gastrointestinal dysmotility or poor gastric emptying.

Nasojejunal tubes

- a long-term nasogastric tube of a longer length than is required to feed into the stomach with or without a weighted end is passed in x-ray under fluoroscopic guidance
- the tube should be secured in position using a barrier product such as hydrocolloid dressings to protect the skin and transparent films
- the length of the tube at the nostril should be recorded, note this does not confirm the position of the tip of the tube
- radiology is the only reliable method of confirming tube position, it is obviously not possible to x-ray prior to using the tube each time
- tube migration or misplacement should be considered if the child/young person is/has
 - vomiting milk feed
 - showing signs of aspiration
 - abdominal distension
 - worsening diarrhoea
 - fluid aspirated from the tube is testing acid on pH paper
 - the tube appears longer or shorter than previously measured
- if any of the above are observed the child / young person should be referred for an x-ray to check tube position.

Transgastric jejunal tube (gastrojejunostomy)

- these tubes are placed endoscopically or radiologically via an established gastric stoma
- the tube is held in the stomach by a balloon which should be inflated with 7-10mls of sterile or cooled boiled water as per manufacturer's guidelines
- the water should be changed weekly as for the balloon retaining gastrostomy tubes
- if the balloon bursts the tube should be taped in place if possible and seek medical advice.

PEG-J

- a percutaneous endoscopic gastrostomy tube with a jejunal extension passed endoscopically or radiologically through.

Daily care

- keep skin clean and dry
- **do not** rotate jejunal tubes
- feeds should be administered via the jejunal port of the tube
- medications can be given via the jejunal or gastric port, you will be advised by your care team as to how to administer medications for your child/young person
- the tube should always be flushed with the recommended amount of cooled boiled water before and after feeds and before and after medications
- tube migration or misplacement should be considered if the child/young person is/has
 - vomiting milk feed or milk is draining out of the gastric port
 - showing signs of aspiration
 - abdominal distension
 - worsening diarrhoea
- if the child/young person has problems with gastric distension a drainage bag can be attached to the gastric port to allow venting and drainage of their stomach.

Appendix 4: Troubleshooting

Gastrostomy or jejunostomy tube blockages

- use a 50ml syringe to attempt to gently flush (push/pull to instil) the tube using warm water or soda water (at least 10mls)
- gently squeeze the tube between fingers and along its length (ie milking the tube)
- if the blockage persists, very gently draw back on the syringe and then attempt to flush as before
- if still unable to unblock tube, consider changing tube, if PEG seek medical attention (sodium bicarbonate may be prescribed)
- establish reason for the tube blocking and check parents/carers information about flushing the tube.

Treatment of overgranulation of gastrostomy or jejunostomy site

Insufficient rotation of the gastrostomy tube or movement of the tube can cause granulation tissue. The overgranulated site may be constantly wet, bleeds easily on contact and is prone to infection²⁹.

A non-traumatic approach to the prevention and treatment of overgranulation tissue should be adopted³⁰.

- ensure that the external fixator device is secure
- swab site for bacterial presence
- excessive moisture can be controlled by using an absorptive dressing
- steroid based, antibiotic or anti-fungal cream may be prescribed to be applied to the gastrostomy site; oral antibiotics may be prescribed if cream is not effective.

Other problems

- parents / carers should be aware of the need to report problems of vomiting, diarrhoea, constipation, abdominal distension, cramps, nausea or dehydration, weight loss or rapid weight gain; these factors may indicate a need to alter the child/young person's feeding regimen or diet¹⁸.
- leakage of feed/gastric contents around the gastrostomy tube and onto the skin at the gastrostomy site will cause skin redness, excoriation and breakdown as the gastric acid contents burn the skin:
 - check balloon is properly inflated
 - pull gently on the tube until resistance is met and secure external fixator
- yeast infections - swab site and treat as per local policy
- If the child/young person is having problems with recurrent burst balloons or leaking valve ports a gastric aspirate should be taken and sent to check for the presence of yeasts. If yeasts are present this should be treated with Fluconazole.

Appendix 5: Administering enteral tube feeds

Positional during feeding

Where possible the child/young person should be positioned with their head above the level of their stomach, preferably sitting or supported at an angle of approximately 30°³².

- infants may be fed in baby seats offering firm support, such as car seats, which should be used in preference to bouncy chairs which can induce vomiting
- if the child/young person shows any signs of shortness of breath (more than usual), sudden pallor, vomiting or coughing stop the feed immediately and seek medical attention.

Gravity Bolus feeding

Allow refrigerated feeds to reach room temperature, before feeding (up to 30 minutes) to avoid stomach cramps

Follow principles of good hand hygiene before, during and after the procedure

- prepare feed and equipment in a clean area
- always check the expiry date on the bottle, pack or tin and gently shake the contents before use
- explain to the child/young person that they are going to have their feed
- if giving feed via a nasogastric tube check position of tube
- for powder feeds follow dietitian's instructions regarding reconstituting the feed
- ensure the child/young person is positioned correctly for feeding
- attach syringe without the plunger to the feeding tube
- flush the feeding tube with recommended amount of cooled boiled water
- slowly pour the amount of feed required into the syringe
- if the feed is running too quickly or slowly alter the height of the syringe slightly, a feed should take between 15-30 minutes to complete
- when feed finished, flush the feeding tube with recommended amount of cooled boiled water
- remove the syringe replace the end cap.

Pump feeding

- wash your hands before and after the procedure
- prepare feed and equipment in a clean area
- always check the expiry date on the bottle or pack and gently shake the contents before use
- ensure pump is positioned according to manufacturer's guidelines
- explain to the child/young person that they are going to have their feed

- if giving feed via a nasogastric tube **always** check the tube position before feeding
- ensure the child/young person is positioned correctly for feeding
- flush the feeding tube with the recommended amount of cooled boiled water (or sterile water where applicable)
- set up the feed, ensuring that air is expelled from the giving set and set the feeding pump according to the manufacturer's instructions either for a continuous ongoing feed or set time/volume limit for continuous bolus feed
- where necessary decant the required volume of sterile feeds (ie pre packed feeds) at the beginning of a pump feed and do not top up feed containers until container is almost empty
- when the feed is completed flush the feeding tube with recommended amount of cooled boiled water, replace the end cap.

Infection control, storing feed and equipment

- avoid touching any internal part of the feed container and giving set, such as the spike with your hands (non-touch technique)
- pre-packed liquid feeds are sterile until opened so they can be used for up to 24 hours, if good hand hygiene is employed. Pour any unused feed down the sink after the container has been open for 24 hours
- powdered feeds and feeds that have extra ingredients added should not be used for more than 4 hours in hospital^{33,34}
- it is good practice to encourage carers to make up each bolus of powdered feed immediately before tube feeding at home during the day, whereas most centres would advise carers to hang up to 12 hours powdered feed for continuous infusion, overnight at home
- feed containers should not be topped up with sterile feed once feeding has started. Instead, the total volume should be decanted at the start of any 24-hour period of feeding
- any unused feed should be discarded after the above time periods.
- giving sets should be changed after 24 hours and not reused
- rotate stock so that it does not go out-of-date
- store equipment and powdered feeds in a dry place as per manufacturer's instructions
- avoid stacking feed next to radiators or in direct sunlight
- avoid storing feeds or equipment in garden sheds or garages during the winter when there is a risk of supplies freezing
- discard feed that is out-of-date by pouring it down the sink
- opened packages of feed can be kept covered in the fridge for 24 hours.

Tubes not used regularly should be flushed daily to prevent them becoming blocked

Giving medication via feeding tubes³⁵

- discuss with a pharmacist the medication requirements for any child/young person who will have to receive regular medication via nasogastric/gastrostomy tube
- the prescription should state the route by which the medication is to be given; the absorption of some medicines can be adversely affected by the presence of enteral feeds
- use liquid medications wherever possible
- flush tube with recommended amount of cooled boiled water (or sterile water) before administering medications, between each medication and after all medications have been given³⁶.
- if medication is only available in tablet form check this can be crushed as the efficacy of some formulations can be impaired or lost by crushing³⁶.

Appendix 6: Nutritional monitoring for home enteral nutrition

Monitoring of growth parameters and nutritional requirements of paediatric patients on home enteral nutrition is based primarily on individual patient need. There are no evidence-based guidelines regarding biochemical, growth and clinical monitoring in this patient group. The following consensus guidelines, developed in a tertiary referral centre and contributed to by current reference group, are based primarily on clinical experience. (ref Lothian BPS doc feb 2007)

Aim: A comprehensive monitoring service helps establish and maintain patients in their home environment, wherever possible, and should be provided at regular intervals by key members of the nutrition support team – most often paediatric dietitian or paediatric nurse. The following should act as a guide to minimum standards for frequency and content of monitoring.

Reviews should occur either in the child's home, school, out-patient clinic or by telephone. If face to face contact is logistically difficult, an identified health care professional locally, should also provide regular input and feedback to relevant member of the nutrition support team.

Frequency:

Initial review :	within 5 working days of discharge on tube feed
2nd review :	2 weeks for 0 to12 months and 1 month for >12 months, post initial review
Ongoing reviews :	0 to12 months = 2 monthly 12 months to adolescence = 3 -6 monthly as dictated by age, growth rate and feed tolerance

Growth parameters: Infants (<2 years)

Naked weight, length and head circumference should be measured and accurately plotted on a standardised centile chart, and corrected age for prematurity should always be used for infants born <37/40 until 2 years. As a minimum standard, growth parameters should be obtained and considered at 2 weeks post tube placement then at the above frequency.

2 years – Adolescence

Weight and height should be measured and accurately plotted on a standardised centile chart 1 month post tube placement and then at the above frequency.

Anthropometry such as mid upper arm circumference (MUAC) and tricep skinfold thickness (TSF) may be a valuable tool to monitor in specific patients where more detailed information is required.

Clinical monitoring

At the recommended review intervals the following points should be discussed and considered.

- nutritional assessment
 - intake from enteral feeds and oral diet
 - nutritional requirements adjusted for weight/age/stress factors /physical activity
- general condition, appearance, energy levels
- gastrointestinal function
 - vomiting/reflux
 - bowel frequency/consistency
 - abdominal distension/pain
- check fluid status
 - include feed, water flushes/boluses, oral diet, medicines
- infusion rate and pump
- feed regimen
 - consider amendments to tolerance and timing of daily activities
- home delivery service
- medicines and drug/nutrient interactions
- check feeding tube and stoma site
- ensure adequate support in community

The key goal with any aspect of enteral tube feeding should be, wherever possible, to improve quality of life by working feed regimens and cares around normal social activities to compliment lifestyle.

Biochemical monitoring

Any child receiving at least 50% of their daily nutritional requirements as enteral tube feeds should have blood collected for the following biochemical tests:

Baseline evaluation:

- Urea and electrolytes, creatinine, glucose, liver function tests
- Calcium/Phosphate/Magnesium
- Albumin/Protein
- C-reactive protein, full blood count
- Zinc, copper, selenium (2ml LiHep in tube with push-on cap)
- Vitamins A/D/E (2ml LiHep)
- PTH (1ml EDTA)
- Vitamin B12/folate (1ml plain)
- Ferritin (0.5ml LiHep)

It is recommended that the above bloods are repeated at 6 months after baseline and then annually thereafter.

If biochemical imbalances or deficiencies/excessive levels of individual nutrients are identified, then closer intervals for reassessment may be appropriate.

Urinary sodium and creatinine will often be a useful measurement in infants with stomas, short bowel syndrome, gastroschisis and cystic fibrosis. The frequency should be based on individual patient need.

Appendix 7: Training Checklists: child/young person/parent/carer

The following are examples of training checklists that may be used or adapted for use in your area. They highlight issues that may be useful in practice. Downloadable at: www.nhshealthquality.org

i Passing a (long term*) nasogastric tube

Procedure								
Steps	Discuss		Demonstrate		Performed with Supervision		Performed Independently	
	Learner	Trainer	Learner	Trainer	Learner	Trainer	Learner	Trainer
Initial & dates								
1. Effective hand hygiene								
2. Collect tube and equipment								
3. Explain procedure to child/young person								
4. Measuring the tube								
5. Passing the tube								
6. Confirmation of position								
7. Securing tube								
8. (Remove guidewire*)								
9. Flushing the tube								
10. Drug administration								
11. Advise on possible problems including tube blockage								
12. Cleaning of equipment								
13. Disposal of clinical waste								
14. How to seek help or advice								

ii Using a nasogastric tube for feeding

Procedure								
Steps	Discuss		Demonstrate		Performed with Supervision		Performed Independently	
Initial & dates	Learner	Trainer	Learner	Trainer	Learner	Trainer	Learner	Trainer
1. Effective hand hygiene								
2. Discuss feed hygiene								
3. Collect equipment								
4. Explain procedure to child/young person								
5. Wash hands								
6. Position/prepare child/young person								
7. Check position of tube								
8. Flushing the tube								
9. Check feeding technique								
10. Drug administration								
11. Advise on possible problems including tube blockage								
12. Cleaning of equipment								
13. Disposal of clinical waste								
14. How to seek help or advice								

iii Care of the child/young person with a PEG tube

Procedure								
Steps	Discuss		Demonstrate		Performed with Supervision		Performed Independently	
Initial & dates	Learner	Trainer	Learner	Trainer	Learner	Trainer	Learner	Trainer
1. Effective hand hygiene								
2. Discuss feed hygiene								
3. Collect equipment								
4. Explain procedure to child/young person								
5. Position/prepare child/young person								
6. Check position of tube								
7. Check gastrostomy tube								
8. Flushing the tube								
9. Check feeding technique								
10. Drug administration								
11. Daily care of tube								
12. Advise on possible problems								
13. Cleaning of equipment								
14. Disposal of clinical waste								
15. How to seek help or advice								

iv Care of the child/young person with a balloon gastrostomy tube

Procedure								
Steps	Discuss		Demonstrate		Performed with Supervision		Performed Independently	
Initial & dates	Learner	Trainer	Learner	Trainer	Learner	Trainer	Learner	Trainer
1. Effective hand hygiene								
2. Discuss feed hygiene								
3. Collect equipment								
4. Explain procedure to child/young person								
5. Position/prepare child/young person								
6. Flushing the tube								
7. Check feeding technique								
8. Drug administration								
9. Checking and changing the water in the balloon								
10. Replacing the tube								
11. Advise on possible problems								
12. Cleaning of equipment								
13. Disposal of clinical waste								
14. How to seek help or advice								

Appendix 8: Audit Tool

This audit tool is adapted from:

NHS Quality Improvement Scotland Best Practice Statement: Caring for children and young people in the community receiving enteral tube feeding reviewed and updated 2007 (available at www.nhshealthquality.org)

In some sections the audit tool provides lists of data to be recorded. Best practice suggests 100% of information should be recorded. It is for each user to agree what the base-line acceptance will be ie what percentage would count as meeting the criteria.

This audit tool is intended to be used as part of the audit cycle. This can be described as the use of audit to identify areas for improvement, drawing up a plan and implementing improvements in these areas, and re-auditing to evaluate and define areas for further improvement. This should raise the standard expected with each cycle of audit.

This tool may be used by individuals to audit their own practice or adapted by organisations to audit their enteral tube feeding service for children/young people.

Yes No Action

Assessment and support

Has the child/young person received a full nutritional, physical and developmental assessment?

Has an assessment been made of the parents'/carers' ability to undertake tube feeding at home?

Is there evidence that the child/young person/parent/carer has been involved in discussions relating to their care?

Is there evidence of multidisciplinary input to care planning?

Planning and co-ordination of care prior to discharge from hospital

Have parents/carers undertaken a training programme of tube feeding procedures and techniques?

Have parents/carers demonstrated tube feeding procedures and techniques taught to them?

Has a home visit been carried out?

Equipment and supplies

Do parents/carers know the procedure for ordering supplies?

Do parents/carers have an emergency contact number?

Are parents/carers aware of guidance relating to items marked single use and single patient use?

Do parents/carers have written information regarding how to dispose of clinical waste?

Care of the gastrsotomy/jejunostomy site and tube

Have parents/carers received information relating to the procedure for maintaining healthy skin?

Are parents/carers aware of potential problems that may occur and what action to take if problems do arise?

Oral care

Have parents/carers received instruction on the most efficient way of providing oral care depending on the child/young person's needs?




	Yes	No	Action
Tube feeding at school			
Does the child/young person have a school health care plan including guidelines for administering feeds?	<input type="checkbox"/>	<input type="checkbox"/>	
Does the school have guidelines on what to do if the tube falls out?	<input type="checkbox"/>	<input type="checkbox"/>	
Follow-up care			
Is there documented evidence of a long-term plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	
Is there documented evidence of anthropometric monitoring?	<input type="checkbox"/>	<input type="checkbox"/>	



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